[0:00:00]

[redacted]

Interviewer: Alright. So can I start by asking you what's been your contact with Huntington's disease? How have you become in contact with the disease?

Respondent: Well, initially back in [2005-2010] when my late wife, [Name 2] was diagnosed with HD, and then further to that we both joined the [Location 1] branch of the HDA. Pretty soon after that, we were regular attendees at the branch meetings and events for five or six years. [Name 2] unfortunately deteriorated quite rapidly in about 2014 -15. Really spent the last year of her life in, well, a mental health unit for part of that, and then the [hospital redacted] in [Location 2]. So yeah, I mean really from [2005-2010] to when [Name 2] passed away in [2015-2017], but I've remained on the [role redacted] of the HDA branch in [Location 1]. So yeah, I mean, quite a lot of contact over quite a long time.

Interviewer: Okay. Okay. So although [Name 2] passed, you've kept basically close contact with people with Huntington’s. Alright.

Respondent: Yeah.

Interviewer: Then how did [Name 2] end up in [Location 2] at the mental health unit?

Respondent: Well, it was [2010-2015]. Well, we managed to get her on the list for the community psychiatry team in the town where we lived, and there's a very good lady there who would see [Name 2] every three months, and we were keeping on top of the mental health issues associated with HD. Unfortunately (sighs), for some reason, and I think it was a dictate from the government at the time, all about austerity, an awful lot of people seemed to get discharged and [Name 2] was one of those. And we then had about a year where [Name 2] had no mental health support at all. Her mental health went down very rapidly towards the end of that year. I went back to a GP, we were pretty much in a crisis situation. We had a few visits from the crisis team, and [Name 2] was effectively taken into a secure mental health unit and sectioned in [2010-2015].

She spent seven or eight months in that unit. We just could not get her out. We could not get her out. They wouldn't let her come home and they had no plan really to move her on to anywhere else, and they couldn't look after her in there. Her physical health then started to decline very rapidly, and in the end, with the help of a solicitor and a lady…oh, I've forgotten her name. She was part of a community mental health team, but she really, really took up the baton for [Name 2] and her and the solicitor managed to…Well, I had to do an awful lot of running around to find somewhere for [Name 2] to go. You know, no one helped me to do that, any of that.

But the [HOSPITAL REDACTED] , who I'm sure you've heard of, an amazing place, absolutely fantastic place, they came and saw [Name 2], someone from there came and saw [Name 2] and they said, yes, we would definitely take [Name 2] and we have a place. And at that point we managed to get [Name 2] out of the… it was called [Name 3] in [Location 3] for the mental health unit. And yeah, [Name 2] moved to [HOSPITAL REDACTED] . She was only there, unfortunately, for about three or four months. You know by the time she got there, she was very, very poorly. You know, her BMI was, I don’t know, it was about 13 or 14, stopped eating. Mentally, very, very confused, lots of psychosis.

The decision was made to give her a PEG because she basically stopped eating and she had, well, even that was a disaster. She was initially taken into [Name 4] to do it under a local anaesthetic and I told them very clearly, there's no way [Name 2] will let you do this under a local anaesthetic. If she's awake, she will not let you do this. And they took her into theatre and she basically kicked up an enormous hell of a fuss, blah, blah, blah. They couldn't do it as I told them, they would not be able to do it under local anaesthetic. So she then spent another two weeks before they rebooked her to do it under general aesthetic, and there's all this time she wasn't eating, and her mental health was just absolutely shot to pieces. I mean, that experience in that theatre I think really terrified her.

[0:06:11]

I've never seen anyone so scared in my life. When she came out of that theatre she was shaking and she was just uncontrollably terrified. She had no idea what was happening to her. And it was a further two weeks to I took her in under general aesthetic, put the PEG in, and she passed away a day later from postoperative infection. But by that time, I mean her BMI was just even lower than, I can't remember what it was when she passed away, but I mean, she was literally skin and bones. So it wasn't, I mean, they had explained there was a big risk, but I think at that point she was so weak that she couldn't cope with the operation. And that really was her very, very sad story because she was terribly let down by the system. She really was.

I mean, in this day and age for it to have played out like it did, you just have to sort of say, well, it just shouldn't, it just shouldn't happen like that. But it does. You know, I think [Name 2] was very unlucky in lots of ways. She was lucky in some ways because she had me to fight for her, but it shouldn't happen like that. It really shouldn't. And it was in my opinion, you know, the overall failing is that nobody takes overall responsibility and sees the bigger picture and coordinates stuff. It was just firefighting with [Name 2] all the time. And because people just do their own bit in their own box, they don't, you know (sighs). Especially with HD, you know, it's the whole person and it's a whole suite of issues that they have. And you know, I do trace the initial mistake back to her being discharged from mental health support in the community because at that point her mental health started to deteriorate, led to a crisis at home, led to her being sectioned, led to her being in a place which was okay (sighs), well just completely unsuitable for her. But because she was sectioned she couldn't come out. They don't seem to have any ability to reach out to, well, it was very difficult for them in that mental health unit to reach out to the wider health service and get support. You know, it doesn't seem to work like that. You know (sighs).

And then it really was at the point where they very clearly, it was very clear that [Name 2] was going to die in that unit. Her physical health was deteriorating rapidly. And I think it was only really at that point they said to themselves “Well, we don't really want [Name 2] to die in this unit because we'll look even worse than we are.” And at that point, you know, it was where can she go to etc. etc.? And as I said, I found the [HOSPITAL REDACTED] , nobody else did.

There were a couple of other places that could have taken [Name 2]. She was a real, on the scale of Huntington's sufferers, [Name 2] was a 10. I mean, she needed complete and total support in a really specialised unit and the [HOSPITAL REDACTED] was probably one of the only places in the country that could deal with that. But she got there too late.

Interviewer: Before this domino, sounds like a domino effect happened from the moment she was discharged from the mental health community team, where were you living when she was getting this mental health community support? Were you still in [Location 1] or were you somewhere else?

Respondent: No, [Location 4] in [Location 1]. We lived in [Location 4] in [Location 1] the whole time it's happened.

Interviewer: Okay. Okay. So when you were trying to take her out from the secure mental health facility, but they were like so basically at some point they wanted her out, but it's not like they could advise you on where should she go, so you were basically doing all that by yourself, looking for a place for her to go, and then the best you found was in [Location 2], so you had to?

Respondent: Yeah, I wanted [Name 2] to come home for a long time and they spend a long time putting support package together and then find that [Name 2] had actually deteriorated further, so they needed to revisit the support package. So we got onto a cycle of, well, we just never got to the point where she could come home and (sighs) you know, rightly or wrongly, I felt that [Name 2] should come home because we had two young daughters at the time, and [Name 2] still wanted to be their mother. I didn't want her to go in somewhere and be apart from us. So for a long time I kept fighting for her to come home, but it just didn't get, you know (sighs). It took too long to organise anything, and by the point something had been organised [Name 2] had moved on.

[0:12:00]

Interviewer: Yeah, she was too deteriorated. Yeah.

Respondent: So it got to the point where we all said “Well, she can't come home” you know, I had to admit defeat and even then I don't think they had any clue as to where [Name 2] could go. I mean, it was really down to me to find places. There was the [HOSPITAL REDACTED] , there's a place in [Location 5] I can't remember the name. And there was a place near [Location 6] and they funded all of this. I mean, she was obviously under whatever they call it, but they funded it.

Interviewer: CHC maybe?

Respondent: Yeah, CHC at this point. But yeah, I mean, I went to these places and a chap from the [HOSPITAL REDACTED] , because they have a specialist Huntington Ward, just said “Look, it sounds like she's in a real crisis. I'll come down and see her.” And he came down in the next few days and said “Look, yeah, we'll definitely, yeah [Name 2] needs to come to us.” And it happened relatively quickly in the end, it's the only part of the process that ever did. But I can't speak highly enough of the [HOSPITAL REDACTED] , I thought they were amazing.

Interviewer: Why do you think she was discharged from the mental health community team? What happened there for her to be discharged? She was well or?

Respondent: No, the reason they gave was that she was stable. But as we all know, Huntington's is a continual deterioration. You know, someone might appear stable for a while, but that's not the case because the disease is always progressing. I know, okay, I've spoken to a psychologist who worked in the same service at the time who told me off the record that the psychiatrist who discharged her, she was moved to a new psychiatrist. The psychiatrist who discharged her was deliberately following a directive to discharge as many people as he could. I was told this by a colleague of his, it was all of around the time of austerity “Get people off our books.” I made a complaint to GMC about this person, which they rejected. They refused to investigate it. But I was told by a colleague that he was deliberately discharging people, up to 90% of the patients on their books just to get them off their books. No assessment of whether they needed to remain or anything.

He saw [Name 2] with her mum and just said “You’re stable. You don't need any mental health support, we’re discharging you.” And I (sighs) we couldn't believe it at the time. Then she was okay for a few months, and then things started to deteriorate. She had terrible psychosis. She'd shout and scream and yeah, get very angry, which is very upsetting for the kids. That started to get worse and worse. I went back to the GP. Delay, referral, delay. Two or three months pass, you follow up, you say now it's becoming really urgent. It's critical. By the time she got seen again, it was getting to the point where we'd had one or two incidents where I'd had to physically restrain [Name 2] in the house. You know, we were in an absolute crisis point, and it was too late at that point. And that's when (sighs), yeah, she ended up going to [Name 3] within a few days of that (overspeaking).

Interviewer: Yeah, go ahead.

Respondent: So I couldn't get her seen again quickly enough. But the initial discharge, as I say, I was told was nothing to do with her illness. It was a deliberate policy, and this particular doctor was widely known as a guy who was just discharging people without (sighs), yeah, without any assessment, contemplation of their needs. He was just following some sort of directive which they had been given. The GMC refused to investigate it. They said that I hadn’t, I think I failed to complete the complaint. I think I failed to tick a box or put the complaint in quite the right format. It was a bureaucratic mistake I'd made, apparently an administrative mistake, but they clearly just did not want to investigate it.

[0:17:21]

Interviewer: That’s true, yeah.

Respondent: I know the name of this guy. He's [Name 5]. I can find him, but in my opinion, he's partly responsible for what happened to [Name 2] after that.

Interviewer: I mean, presumably there's a whole lot of people that went through the same, well, speedy discharge and God knows what happens.

Respondent: Yeah, I mean, the wake of destruction that would've caused is frightening to think about.

Interviewer: And even at cost level, I don't understand, you know, it would've been much cheaper to keep having the mental health team checking on [Name 2] than sending, you know, what ended up happening was way more costly, even without caring about the people. But if they're just looking at money it's not even smart.

Respondent: Oh, it doesn't make sense on any level, you know. In terms of looking after people, the effect on their families, the economics, none of it makes any sense. I mean, look, [Name 6], I'm sure you are passionate about joined up care, but I mean, joined up care makes so much sense on all of those levels. You know, you've got one person like [Name 2] in 10 different mental health units, if you could have them all together in a place that specialised in looking after them, yes, it's a bit further for people to travel, but I would've always felt much happier if [Name 2] had been somewhere where I knew they could look after her and it was further to travel than, you know, a place a few miles away, which couldn't, you know (sighs). Yeah, it doesn't make any sense. And joined up care does on absolutely every level.

Interviewer: So how do you see it looking ideally, you know, what sort of things you think should be in place? You've mentioned like that you should have like a specialised unit for people to go to that they get that person-centred view and they're looking after their mental and their physical health, even if it's a bit far, that would be reassuring.

Respondent: Yeah. Well, I don’t know, this is just my thought, but I mean (sighs), you need a multidisciplinary team with specialism in HD. And if that team had both an outpatient and inpatient facility, so while people are in the earlier stages or whatever of HD and able to live and look after themselves with a bit of help and all the rest of it, you know, they see them in the outpatient aspect. But there does come a time quite often where the sufferer does need to go to somewhere. And again, I think that has to be somewhere with specialism in HD because it is a really complicated disease and it does affect people differently. And what I saw in the [HOSPITAL REDACTED] was a multidisciplinary team of people who really understood HD. And I sat in on one or two of their team meetings about [Name 2], and it was amazing. I mean, there was the lady who runs the gardening there and she had just as much say as the psychiatrist because looking after people of HD, you know, it's all about managing what they’re feeling, how they're coping and doing gardening is amazing because, you know. And probably better in a way than some of the drugs that psychiatrists could prescribe.

But even the nurses and the health assistants there, they were so good with [Name 2] and so good with everyone there, and because they understood HD. And you don't get that if you've got people spread out all over the place in different places. And I'm sure, you know, (sighs) everyone in the NHS I know I think they're all heroes. I think they all go into work to do their best for people, but they might only come across someone with HD a handful of times in their career, and especially people with the extent of problems that [Name 2] had. I mean, she did post a lot of challenges, and it's really difficult to explain to people. I mean, when we had numerous times where she had to go into hospital, and you sit there and you try and explain in A&E what [Name 2]'s like, and you get somebody say “Oh yeah, I've worked with somebody with HD before.” “But you haven't. I promise you, you haven't worked with [Name 2] before. Whatever you think you know, okay, please listen to me” and I found that you didn't get listened to an awful lot of the time.

[0:23:00]

I remember when she was on the ward and we were trying to feed her, and they tried to put a tube up her nose and I said “She won't take that. She won't take it.” “No, we're going to put a tube up her nose.” We spent the next two hours trying to hold her arms down. And that time when they took her in to do the PEG under local anaesthetic, I mean, I'm not being funny, can you imagine if you were kidnapped in South America and taken into a room to have your tummy cut open, you'd think you were being tortured. I think that's what [Name 2] thought was happening. I've never seen anyone as terrified in my life after that. And I told them it just wouldn't happen. If I'd realised how bad it was, I would've done something to stop it. I didn't realise [Name 2] would react quite that badly, but I did say to them “This is not going to work” but you don't get listened to.

Interviewer: Yeah, I'm getting this a lot, that you know your loved one the best. You may not be a neurologist or a psychiatrist, but you're the expert on that person. Yeah, you're not, well, I'm sure you know you're not alone on this with these thoughts, Then you were saying there's no one to take over the overall responsibility about the person's care. Do you think such a role would help, like to have a care coordinator or whatever we want to call it?

Respondent: I'm a big fan of the multidisciplinary team. I know there are people who are, you know, a point person as a care coordinator, I think would be a massive, massive improvement on where we are now. But I still think that that person, despite their expertise, still has a bit of a challenge in trying to coordinate all the services that are needed, which is why ideally in my world a representative from each of those services would be part of a multidisciplinary Huntington's disease. And I'm not saying they're a permanent sitting body, but they are you know, for that area they are the HD multidisciplinary team, and they meet regularly and they have their patient list, etc. But because they're all coming from the services that need to be involved there's an automatic, hopefully, much smoother path to accessing those services. Whereas a care coordinator, and I don’t know how this would work, [Name 6], you probably, I mean, look, I'm speaking as somebody who doesn't really know how the system works, but they still face the challenge of trying to pull those services together. I mean, [Name 7], you'll know [Name 7] really well, aren't you?

Interviewer: Yeah.

Respondent: Yeah. I mean, she obviously is a real expert in HD, and I know she works for the charity, not in the NHS, but all she can do is sort of tell you to try and access this service and try and access that service. She's still got the problem of disparate services and different advice, and no one really overseeing everything around that person. And I think a care coordinator would be a definite improvement, a massive improvement, because if I think back to [Name 2]'s experience, the person who was closest to that role was her neurologist, but we only saw her every six months, every 12 months. And actually effectively, apart from writing letters to people, she couldn't do too much.

So (sighs) and sorry, one of the other terrible things, and it was all timing, and [Name 2] had an awful lot of bad luck when things got to crisis point with [Name 2], her neurologist who'd known [Name 2] since [2005-2010] and had originally diagnosed her was on maternity leave for a year, so she I'm sure would've been able to help me a bit at that time, but she wasn't around, so you know it was just-

Interviewer: She didn't have any, I mean, she went on maternity leave, okay. But so who? Were you directed to someone else, to another?

Respondent: We saw her replacement, who basically knew nothing. I didn't think too much of him. We spent a half an hour with [Name 2] at [Location 7], and he was looking things up in a textbook. So at the time (tuts) he was certainly not the top of my list of people to go to, to help. Yeah. I mean, we basically lost that sort of neurology support (sighs), well, at the worst possible time.

[0:28:35]

Interviewer: Yeah. Well, yeah, that's another issue. Yeah. Okay. So you had someone that could have helped, but they weren't available and whoever was put in place wasn't suited for the job. So either way was no help there.

Respondent: Yeah, I mean, I didn't contact this guy when things were going wrong. I would've contacted [Name 8] definitely if she'd been around, but I knew she was on maternity leave.

Interviewer: Well, yeah, I see your earlier point of even if there's a multidisciplinary team and there's a coordinator, a care coordinator within, there's still the difficulty of like if you need, for example, to contact social services to get hold of the right person on the social services to speak to. So as much goodwill the care coordinator can have, it will still spend a long time trying to reach the right people. So you're saying we should have a link, like an HD link in the different sectors so that when something happens we know within that sector who should we be speaking to?

Respondent: Yeah, so in my multidisciplinary team, I would have somebody from social services. I'd have someone from community mental health. I'd have inpatient mental health, I'd have speech and language. I'd have as many different services as possible really on that MDT team so that when that person, when that sufferer presents in a certain manner, you've already got somebody on the team looking after them representing the service that they need to access. That would be my ideal.

Interviewer: Was there a social services person at the [HOSPITAL REDACTED] ?

Respondent: Well, she's obviously at that point she's an inpatient, so it's less relevant.

Interviewer: There was less of a need.

Respondent: She wasn't going to come home at that point. So no, there wasn't. I mean, the [HOSPITAL REDACTED] is really it's for inpatients, isn't it? I think if you've got Huntington's and you end up in the [HOSPITAL REDACTED] and you're not coming out again, are you? So (sighs) yeah. But that multidisciplinary team what I saw at [HOSPITAL REDACTED] was so broad. Like I say, the gardener was part of it, the music person was part of it. You know, it did cover everything that you could want covered really.

Interviewer: And then so you said that when [Name 2] was at home and before the crisis just started, you said you had small children, two children. How old were your children more or less?

Respondent: So [Name 9] was [2000-2005]. [Name 10], [2000-2005]. So when the crisis was happening, [Name 9] was 9-12. [Name 10] was a year younger. Yeah, I mean, they were pretty young. I know what was happening at home was very upsetting for them. [Name 2], part of her psychosis was that she felt that people were…she was very fixated about toileting. She felt that people were taking the Mickey out of her. And she actually, unfortunately for some reason, felt that her children were so she used to get very angry with them. Now I think I shielded them from the brunt of that, but I did have to a couple of times in the middle of the night stop [Name 2] from going upstairs to their bedrooms. She was very angry about stuff and I had to stop her from doing that. And that's the point really where I just said, you know, we can't cope with this at home.

Interviewer: Did you have any help to protect the children or to manage your daughters?

Respondent: We had a care package and there was a social worker involved, but two carers effectively said they couldn't cope with looking after [Name 2] anymore, and they pulled out. So I was left on my own really. I don't blame these two ladies. I mean, crikey, [Name 2] was a real handful at this point, and they're just care workers. I'm not saying just care workers, I mean these people do a great job, but I think this was above and beyond what you'd ask somebody to do. It's not like going in and giving someone their dinner and helping them into bed. It wasn't like that.

[0:34:01]

Interviewer: So you had these two ladies coming, or these two people coming in and the care package had been set up by the social worker, and then the ladies were like “We can't care for [Name 2] like this, it's not sustainable.” So what did the social worker do then?

Respondent: Nothing. Couldn't put anything in place, didn’t really. She said, “[Name 2] has to go into a home” and I said “Well, no, I really want her to stay at home.” And I said “Look, the reason why this is happening is because she's not getting any mental health support because she’s being discharged.” But as far as the social worker was concerned, because they’re all about risk, aren't they? They’re saying “No, she needs to go into a home.” Very frustrating for me because I could see that it was a lack of mental health support that really led to this, and it was forcing [Name 2] out of the family house. Again, just nothing was joined up. You know, I can see the social worker's point of view, but it is only as a consequence of [Name 2] being stopped in other areas.

Interviewer: As far as you know, it's not like she called the mental health team or called the GP to get a?

Respondent: Oh, I had the GP on. I mean, the GP was desperately trying to get [Name 2] some help, and she did see the psychiatrist in the community, but it was just too late. I mean, it was too late. It should have happened... She should never have been discharged.

Interviewer: In the first place. Yeah. Okay.

Respondent: And I would still love to pursue this guy, but I can't. But yeah, I mean something very sinister happened there, it’s the sort of thing you... One day I might contact Panorama (laughs).

Interviewer: Sorry, what's that?

Respondent: One day I might contact Panorama.

Interviewer: Oh (laughs), well, yeah, it sounds like the sort of thing for them. Okay, so [Name 1] your children are adults now?

Respondent: Yeah.

Interviewer: Right. Are they at risk?

Respondent: Yes. Yeah.

Interviewer: They’re at risk. Okay. Is there anything you want to tell me about what they need or you think should be in place for people at the stage where they are or?

Respondent: Yeah, I mean, I genuinely think if we had a multidisciplinary team covering our area, like the girls could have the option of going in to talk to them. Because even though neither are symptomatic and neither have done the test and know if they are, you know, if they've got HD, even at this really early stage, almost pre HD, they could probably do with some. And I know it is available, I know they can go and see somebody about the test or whatever, but their options seem to be to go down to [Location 8], which is a bit of a trek or [Location 2]. And I think at this stage, neither of them are interested in taking the test, but potentially being able to speak to somebody about the issues around it would help. They seem to be a little bit switched off from HD and you can fully appreciate why. But yeah, even at this stage, you know, knowing that the MDT team were around and covering the area might be a help. And you know, if one of them does have it or both of them have it then that team progressively becomes more involved.

Interviewer: [Name 1] I mean, of course that [Name 2]'s care was like 10 years ago, do you think that the problems you faced then are still current? I mean, you're quite still involved with the HDA and I'm sure you speak to other people that are currently affected. Do you think that pretty much different year, same story or?

[0:38:55]

Respondent: My impression is that nothing's moved on. I made a very detailed complaint outlining all of this after [Name 2] passed away, and the trust involved did do a very thorough investigation involving two psychiatrists, and there was an action plan and all the rest of it. But over the years, obviously it's a long time has passed now, I have no idea if anything came out of that, ever got changed. My impression is-

Interviewer: Which trust did you complain to?

Respondent: Oh god.

Interviewer: Oh, that's okay.

Respondent: Whichever trust runs mental health in our part.

Interviewer: Oh [Trust redacted]?

Respondent: Yes. Yeah, that's it. Yeah. I mean, I've spoken to their executive committee. I did a presentation to them. I've done a presentation to the Royal Society of Psychiatrists. I've done presentations to a neurological alliance. I'm trying to find it, [Name 6], because I've got a really, I think, powerful slide on HD.

Interviewer: Yeah, you have like with all the care. I remember seeing like different people and like there was a lot of like intertwining. I mean, it was a few years ago [Name 1].

Respondent: Yeah. It's for spaghetti slide, it's called.

Interviewer: Oh yes, there's a bunch of like strings. Is that why you're calling it spaghetti?

Respondent: Yes.

Interviewer: Yeah, I think I remember seeing that.

Respondent: Yes.

Interviewer: Vaguely, yeah. I mean, if you don't mind sharing it, I would still like, you know, because I don't have the slide, but just for me to see, not-

Respondent: I will find it.

Interviewer: To send it around.

Respondent: No, please. If you want to use it, use it, please. I mean, I say to everyone, if you want somebody to stand up and talk to an audience about HD, I will always try and make myself available to do that. And I don't care what the audience is, but I am very happy to talk through [Name 2]'s story, my experience and what I feel could and should be improved. And I don't care, you know. I don't particularly care. Like I say, I've done that talk a few times. Very happy to do it again. I have a massive advantage of being a lay person and a carer, so you automatically have the audience completely on your side. But like I say, I'm quite passionate about this.

Interviewer: Well, I think you're going to all lengths to avoid this happening to any other family. So it's truly impressive, [Name 1]. I mean, just talk about turning something negative into something positive.

[0:42:06]

Interviewer: Okay, [Name 1]. Alright. I know we're coming to the hour and I don't want to…I'm going to do a couple of boring questions now that I need to do everyone. How old are you?

[redacted]

Interviewer: Right. [Name 1], is there anything that you want to add to our interview today? Something you thought I would ask you and I didn't ask you that we can go over? I'd like to save the last couple of minutes to go over a bit.

Respondent: Well, I'd love to know, [Name 6], you are obviously working on your study, your project now. Tell me about it please.

Interviewer: Yeah, do you want to know my insights

[redacted]

Respondent: Yeah. I mean, look, [Name 6], I would always be very up for supporting what you're trying to do in any way you felt could be useful. So please bear that in mind. Like I say, very happy to get up and speak to people, don't care who, about all of this. I have actually found the presentation.

Interviewer: Oh, good.

Respondent: Could I just very quickly whizz you through it, because I'd like you to see it?

Interviewer: Yeah, yeah, I have time. I was just because you had said hour, so I was trying to keep it within an hour. Always.

Respondent: Oh, don't worry. On this particular subject (laughs), I'm not going to stick to a clock. Right, come on, go away. Oh (sighs). Can you see my screen?

Interviewer: Yeah. Yeah. So it's not on presentation mode, but I can read. But I can read what it says. Don't worry, so the font is fine.

Respondent: I'd like to stick it on presentation mode. I can't get rid of this toolbar over the top. Go away.

Interviewer: If you click down on the button, so on the bottom right corner of the screen next to the…there's the plus minus thing, but then there's the button with a little screen. So to the left. Left. Yeah, that slideshow there.

Respondent: Oh, right. Wonderful.

Interviewer: Oh, there you go.

Respondent: So yeah, I mean, look, it's a bit of an intro about [Name 2] and myself, but then this is the…why won't this click on? Oh, right. So this is the spaghetti slide. So I've got in the coloured boxes, you've got the Huntington's sufferer in the middle there of the screen, you've got some services and there are other services, but this is just a sample. You've got your dietician, speech and language, neurology, OT and physio, mental health, general medicine, and care and nursing. And then in the other boxes, you've got some effects of Huntington's disease. And again, if you put five carers in a room, they could generate 10 times these number of issues, I'm sure, but this is just an example. So you've obviously got OT and physio will be able to deal with some of these. For instance, they might look at adaptions to help somebody sleep, reduce the risk of infections, swallowing problems, difficulty communicating. You've got general care and nursing who, again, will address lots of these issues as well. I haven't done this talk for a while, so I'm just so, excuse me.

[0:51:22]

Interviewer: Well, no, don't worry. No, for me, this is interesting.

Respondent: Yeah. So again, they're reaching out and they're trying to help with some of these issues that a person suffers. Dieticians speech and language, again, really important over sort of eating and risk from eating, but also communication because a sufferer does start to find it increasingly difficult to communicate, which I know was very frustrating for [Name 2]. Neurology, you know, like I described when we were chatting, our neurologist was kind of holding that overall coordination role, but I don't think in quite the way that it needed to be done. I'm not criticising her at all, but it's just not set up like that. But again, they're sort of trying to coordinate across a lot of issues.

You know, sleep deprivation for [Name 2] was a massive, massive problem. I mean, she probably only had two or three hours sleep a day, which is always going to cause somebody to have lots of other problems. Anger, regulating emotion. That thing that I'm sure you find you come across all the time is very impulsive behaviour. Can't wait for anything. Caring for HD, by the way, is I tell you what, you know, it's a complicated thing to be that carer, you have to be thinking two or three steps ahead all the time. It's a real art in it in its own right.

General medicine, again, lots of infection. You know, dealing with infections. Pneumonia. [Name 2] did suffer from pneumonia at one point. She spent a week in intensive care in St. George's, very, very poorly. I mean, yeah, that was towards the end of that year, the last year of her life. But again, that was eating, and at that point, [Name 2] refused to eat after that.

So general medicine, and then you've got mental health and mental health to me, as I've described, [Name 2]'s journey was the real kicker in terms of that deterioration, which happened quite rapidly. Obviously with HD, things are only going to go one way, but that lack of mental health support I think really precipitated the decline and suffering that [Name 2] had at the end of their life, which was needless and cruel and inhumane in this day and age. And then when you actually put that picture together this is what you get. So you tell me if one person can deal with that, because they can't. You know (sighs) it's impossible, which is why you have to have a joined up, coordinated approach to looking after people with HD. And you know, your point about the finance, each of those services is spending a disproportionate amount of time and effort and money trying to deal with their bits of this. Whereas actually, if you can bring together the overall picture and say “Well, look, why is this patient suffering psychosis about toileting and getting very angry? What can we do to make toileting an easier, simpler, and less intrusive aspect of their life? What drug could they be on to try and calm her emotion? What care and support could assist? What adaptions to the house do they need?”

And all of a sudden from something that's mental health are coming out in the middle of the night to carry you off and section you to something that you can manage and doesn't cause that level of cost, time, heartache, disruption, etc. So, you know, the approach has to be to deal with all of this in a holistic joined up manner because you can see the complexity. This slide shows you the complexity. So a couple of quotes from [Name 11] who ran outpatient psychiatry in [Location 1]. Again, just saying, struggling to get the support from other services, need support from integrated services. The patients with the most complex problems get the most fragmented service. And there you go, you know, I think some of those quotes really-

Interviewer: [Name 1]?

Respondent: Yeah.

Interviewer: Was there? I mean, there's a specialist nurse in Huntington's in [Location 1]. Was she ever involved?

Respondent: Yes. Remind me of her name.

Interviewer: [Name 12].

[0:57:04]

Respondent: Yes, [Name 12] was because I know [Name 12] through the branch. [Name 12] came and saw [Name 2] in [Name 3] when [Name 2] was sectioned. She tried very hard to educate them in [Name 3] about how to look after her. She went through [Name 2]'s drug records in [Name 3] and found that [Name 2], oh, even the drugs situation in [Name 3] by the way, and this is another, you probably sit here, open mouth at this. They weren't keeping proper records of what they were giving her.

Interviewer: No (laughs). That's basic.

Respondent: I mean, we found that she would be switched drug without any notes on the file to say why. I mean, there was [Name 12] catalogued the drugs that [Name 2] was on, and I think I've got some sort of graph or something somewhere. But there seemed to be a very random approach to it, and often I wasn't actually informed when her drugs were being changed, so yeah. But [Name 12] did come in and help with…try and help, try. I don’t know how much traction she had when [Name 2] was in [Name 3]. So yeah, there you go. I think we've discussed all of this complex interaction of symptoms, and they're unique.

There's a quote you might have seen before from somebody who obviously has, you know, worn the T-shirt. If you've met one person with Huntington's, you've met one. Listen to the carer. I think you've, obviously, really come across this a lot. And yeah, I think we're both on the same page that a multidisciplinary approach is the only thing that, I think, at the end of the day is effective. Obviously, if you could have that in an ideal world, you address so many aspects which are wrong at the moment. You know, human suffering, the effect on the family, quality of life, more time that [Name 2] could have had with her kids, and yeah, saves money. You know?

Interviewer: Yeah, yeah.

Respondent: So at the moment (sighs) this is my impression of what currently happens. You have Huntington's disease and those arrows are deliberately pointing out from that person because you have to go and search for all of this support from all of these different services, and then you have to work out what they're all telling you, which might conflict sometimes and work out what you need to do. So very little joined up thinking and approach there. But what you really need is something like that where all of those services form a, sort of, virtuous circle of support around the person. And there you go. I'd like to finish with that (laughs).

Interviewer: Yeah, I think yeah. I mean, again, it really stuck with me, yeah, the spaghetti slide. I think it visually does cause a big impact, and why would the spouse be expected to deal with this by themselves?

Respondent: Well, what terrifies me is so many people out there without a partner.

Interviewer: Yeah, yeah, yeah. And as you said, very rightly, the people with the most complex needs are the ones with the more fragmented care. And actually, there's very little research, including people without carers, because usually they look at the diets. The person with a spouse, with a carer, not the person without. Even for trials, it's many times an exclusion. So actually when I did my first study I saw that people aren't, so basically the people who need it most aren't even being included on the research, so it's very strange. Thank you very much for sharing this with me, [Name 1].

Respondent: Well, I'm going to send this to you, [Name 6], and look, if you want to use any of this, please do. You have my absolute permission and if you-

Interviewer: Thank you.

Respondent: And like I keep saying, if you come across an opportunity where somebody like me could talk to an audience and just go through this, basically, I'm very, very happy to do so.

[1:02:17]

Interviewer: Thank you so much. Well, I might take on your offer. Let's see what I have ahead. I think there was something pencilled from the Neurological Alliance for May. They haven't confirmed yet. I've presented, when was it? January to them. But as you said, it's always so much more impactful when it comes from someone that has lived through it instead of just data and figures. Okay. [Name 1], is there anything you'd suggest me doing differently with future participants for them to have a good experience through the interviews?

Respondent: No. No. I mean, look, you’ve very kindly let me rant away, so thank you.

Interviewer: You didn't rant. You told me what I needed to know, so I'm very thankful for your time and you're even at work. I mean, I can't imagine how you will go back to work after this, but I think you're going to have a big coffee to keep you going.

Respondent: Yeah, yeah. Well, like you say, you've got to try and pull something positive. You know, if you just dwell on what happened, you know, obviously (sighs) it's not very nice to think about, but I've got two kids, two grown young adults who might have to go through the same thing, I don't want them to, so yeah.

Interviewer: Clearly if everyone was like you, I don't think we would have such a big problem. Everyone would be, you know, you're very proactive and you really are doing everything you can for your girls as well. Again, [Name 2], you did all you could for her, but there was a limit to the impact you could have and you're really trying to make the best of a really sad situation and protect your girls from ever going through the same. And I hope they never have to go through anything like this, and well, fingers crossed, I really hope they're negative. But as you said, they're quite living their lives without thinking too much about Huntington's, which is good for now.

Respondent: Yeah. Okay. Thank you, [Name 6].

Interviewer: Thank you so much, [Name 1], for your time. I'll send you an email with the consent.

[redacted]

[End of Transcript]