[0:00:00]

Interviewer: But I think it's my study mobile that is not so great (laughs).

Respondent: We’re not having any luck todays with mobiles and Teams and whatever, are we really?

Interviewer: Well, imagine if we had to do this by letter, so (laughs).

Respondent: I loved that age [Name 1 interviewer] so (laughter).

Interviewer: Okay. So I want to have like a nice chat with you. I want you to be able to be honest, and the whole point on this is that I get a good perception of your experience and your family's experiences with Huntington's disease. So can I start by asking you to tell me a bit about your experience with Huntington's disease so far and how have you become in contact with the disease?

Respondent: Yeah, so my husband, he was genetic tested after we actually, he was researching his family history and ordered a death certificate and found out that Huntington’s, you know, his granddad had died of Huntington’s, which then led him to go and get the genetic test, which unfortunately was positive and he was in his mid-30s at that point and it progressed really quickly. He ended up being in care for nearly seven years and then he died two years ago, and both my children are at risk as well.

Interviewer: I'm sorry to hear that. Yeah, you have told me by email, I mean, it is fairly recent so I do appreciate you taking the time and I think you might feel quite tired after it is done, so I hope you can have a nice cup of tea and just don't do much more for the rest of the day.

Respondent: No. I feel it's really important things like this being [Name 1 interviewer], to be totally honest with you and people engage, because I feel like we weren't given that opportunity because nobody told us about it and everything, so you know. But to me I feel like research projects and options are really important certainly for my girls going forward and that, so yeah. Stuff like this (laughs).

Interviewer: Thank you, and your children, they're bigger, right? I mean, we say children but they're?

Respondent: Well, there’s 10 years between them, you know. That just happened. Don’t know really why. But yeah, so I've got a [20-30] -year-old and a [10-18]-year-old and obviously for their experience of dad being ill and you know and being one are very different because of the large age gap. So my little one was only five really when we sort of like, well she was three when we found out and then I really went... dad went into care almost. Whereas one has got far more memories of him being well or, you know, rather than just being in care and being really quite ill.

Interviewer: So what was your husband's name?

Respondent: It was [Name 2].

Interviewer: So [Name 2] had to go into a nursing home or?

Respondent: Well, this is where actually I'm quite passionate about personalised planning and joined up working. He actually ended up in a secure unit in a mental health hospital and that, so which was a real struggle. He was in there for two years because health and social care didn't work together and the mental health team in that particular trust would not take advice from his psychiatrist and that, you know, his Huntington’s specialist. So ended up having some quite, shall we say, ineffective treatment like electric shock therapy, actually made him worse. So he was in there for two years. He then came out and because he really wasn't stable enough to have at home, had issues around his mental health and whatever and in terms of him being in with my daughters, you know, I sort of like said then I wasn't able to have him home. So he ended up in supported living but then got readmitted and then came out again. So for the 10 years really it was quite difficult. He was either in a secure mental health hospital or he was in supportive social care and live in accommodation.

[0:05:21]:

But I needed the girls to have a positive relationship. So when he would, you know, sort of like mentally more well enough, the Huntington's really affected his mental health and cognitive abilities. He didn't really have much chorea, you know, at all, which is why people really didn't understand that it was Huntington's that was causing the mental health issues rather than it being, you know, and that. So but I needed my girls to be able to see him when he was well because obviously why they were at risk, and the eldest one as you can appreciate was far more aware at the risks, so I needed them to be able to see him in a positive way rather than in a negative. So being in care (inaudible 0:06:15) you know, care going in, you know, we would go around and see him but I could always then, you know, if he wasn't having a good day, I wouldn't take them round. Yeah, trying to protect them as much as possible, but it was difficult because of the lack of joined up work in between health and social care.

Interviewer: And when you mentioned that the mental health team weren't taking advice from the psychiatrist, where was this psychiatrist or this expert team in Huntington’s?

Respondent: Yeah, so basically he ended up in, like I say, a secure inpatient unit and his Huntington's team were based at, so that's in [Location 1] and his Huntington's team were based at [Location 2]. It was a different mental health trust, I mean, in the mental unit, but the actual input was a psychiatrist, you know, half an hour once a week type of thing on ward round. And they literally refused to sometimes even have the HDA in and they refused to talk to [Name 3] who was the consultant psychiatrist for Huntington's who was based at the [Location 3] in [Location 2]. And by the time I eventually got somebody who would talk to them, they spoke once and then it was a local psychiatrist on the ward, they moved on. So it was constantly having to keep revisiting and trying to “Huntington’s, Huntington’s” and then, of course, the problem that you get with mental health is, you know, they judged him and, you know, that he had mental capacity, so consent and whatever. And he did have mental capacity to a certain extent, we're not going to take that away, you know, he didn't lack capacity but he made very unwise decisions and everything. So again, at one point they literally refused to talk to me, refused to have either myself or the HDA in during ward round and that sort of thing.

Then [Name 2] for a long time he continually kept going in and out of psychosis and very dissociative state and that, you know, he thought I was trying to kill him. Come home on a home visit, you know, thought I was trying to kill him. But whatever, you know. So it was very difficult. Then the psychiatrist unfortunately in the mental health unit, you know, would just say “Get the police. Get the police.” You know, and it was just so unnecessary because if had they attributed to Huntington’s and not given things like electric shock therapy, which was never going to work, then I don't think he would've deteriorated, if that makes sense.

Interviewer: So the electric shock therapy was not under the advice of the [Location 2 expert] team?

Respondent: No. No, absolutely not. No, they did that before, they even, would listen to me to try and phone the Huntington’s team. Again, it was me trying to explain to them, and yes [Name 2] can consent to it because he’s in psychosis so it’s disassociation, but the reality is that the proteins building up on his brain it's not going to stop building because you've given him electric shock therapy. So they did it 12 times, it should have been a course of 20, but after 12 times I think they finally realised it wasn't making any difference. So then they stopped.

Interviewer: So when [Name 2] went through his diagnostic test, was this at the [Location 3] as well?

Respondent: No, that was so the genetic test was done in [Location 1], but the geneticist was lovely, but in a way, it didn't help, because she just literally told us there would be a cure within her lifetime.

[0:10:58]

So [Name 2] took that as very positive, and you know what I mean, and everything and that. But it also caused, as I'm sure obviously you know Huntington’s causes a lot of divisions in families. So his blood family, his dad who, you know, well first of all they weren't going to give him the test because his dad had never been tested and the family had split a long time ago and [Name 2] hadn't seen him since he was [10-18]. So they were, first of all, “Well, we can't test you because that will tell you your dad's status.” So [Name 2] had to like argue against that and they finally agreed to do it, which then of course meant his dad was positive too, it caused a lot more divisions in the family and everything. So, you know, we were on our own and didn't have that, sort of, like extended family support and whatever around us. And then, you know, his sister tested positively as well and she blamed [Name 2] for making her go for the test, which wasn't, you know. Nobody could have made his sister do anything she didn't want to, but she doesn’t acknowledge Huntington’s at all. She refuses to have anything to do with it. And his brother tested negative and that, you know, so he's got a lot of survivor's guilt and whatever around it. But since he died, unfortunately since [Name 2] died, the family have completely, you know, his blood family completely don't have anything to do with us really, not something that I push because you know at the end of the day [Name 2] had to deal with Huntington’s and that’s so yeah.

So really following the genetic test we really didn't have any support and that and I had to push quite hard to get [Name 2] into the, sort of, like local Huntington's clinics and everything and they are good and I'm not going to take that away, but they're very limited as well over what they can do because they work in a different NHS trust, they've got no say so, with going across boundaries, sort of like those, you know, sort of like where it used to be clinical commissioning groups, didn't it? I can't remember.

Interviewer: CCG’s

Respondent: That’s it, yeah. But for whatever reason, you know, they don't like working across and what thing, you know, and it can be really difficult to get even local clinics. I mean, because you know even going to [Location 2] first, that's quite a way. [Name 2] sometimes when he was well would also, “Well, there’s no point in me going because they're only going to maybe measure me, whatever, look at my gait or whatever, and actually that's not how I'm suffering.” So sometimes he would disengage from that as well, so you know. But I generally thought, and again you can only do what you think is best at the time, can't you? But I genuinely thought it was better to at least have some Huntington's advice rather than just trying to do it locally, if that makes sense.

Interviewer: Yeah. So you were more keen on going for the reviews than [Name 2]?

Respondent: Yeah, yes, 100%. I mean again, [Name 2] had had operations on his back, he’d had it [inaudible], he’d had lots of, you know, what's the word I'm looking for? We’d had all these problems with his gait and whatever, which looking back was probably Huntington's but were being treated as physical health problems that could be operated on and things like that. And again, probably because there wasn't that joined up thinking and everything and that real disconnect I think between physical health and mental health.

Interviewer: So when he was going with his back complaints or where was he going to with his complaints? The GP. Where?

Respondent: GP and he got two consultants and yeah, but again, physical health consultants, you know, the hospitals and whatever. Again, if I ever, and this is where it's difficult again because [Name 2] at points you know, would go to the sort of like consultations and they would offer him an operation and I would go “Or perhaps maybe we ought to think more about Huntington's” and [Name 2] would then say “No, not even thinking about that. I need an operation.” Do you see what I'm trying to say? So again, as a carer almost in a way it's really difficult when that person does lack insight into what his difficulties actually are.

[0:16:03]

Interviewer:

Yeah, so I mean people that work with patients with Huntington's we know they lack insight, so usually as you're saying, if you ask someone how they're doing, they'll say they're doing well. Or if they ask do you want shock therapy? They'll say yes. Do you want an operation? They'll say yes. And it's many times not in their best interest. But what you're saying is that basically because let's say the orthopaedist is looking at his back and is thinking, “Oh yeah, let's operate” without looking at [Name 2] in his whole self. Yeah. So were these concerns raised with the Huntington's clinical team about his pain or?

Respondent: No. This is again, and this is where it got really a little bit problematical because they [HD expert team] only saw him once every six months or only once a year, yeah, you're absolutely right there, and I must admit I did a really big complaint, actually went to parliamentary health and whatever as well about this. But even if they don't see him once a year because of that, I'm fine, and because of that the mental health difficulties they think…they don't have time to go further into that. And even if I'm sitting there going like (inaudible 0:17:33) and whatever, and a couple of times they sort of like got me and said “Oh you know, [Name 2], you go outside and get weighed” and then I could actually sit and go “Look, actually this is not why, he's not doing this, whatever.” But again, it could then be another year before the next follow up appointment or another six months and then I might not have been able to get him to go. So and I don't think that's any, I mean for me, that's no disrespect to the team because they tried their best but equally again it comes back to that mental capacity. And despite me saying this he, you know, obviously in law he could actually say to me, you know, “Don't listen to her. She tried to kill me today” (laughs).

Interviewer: Oh yes, of course. If you had issues, you know like some crisis, I mean it sounds like you had some crisis either way in between these appointments with the [Location 2] team, when there was an issue, there was a problem, who would you contact?

Respondent: I didn't really have anybody to be totally honest with you because it literally just kept, you know, when it got to crisis it was literally just trying to, I was literally told just get him to A&E and whatever, you know. Get him to A&E and then it’s straight into the secure mental health hospital because it was a mental health issue.

Interviewer: Yeah.

Respondent: And that mutually whereas I, you know, completely felt left on the limb because I was like, you know. But then when I've got somebody, you know, [Name 2] when he went into psychosis he had really bad psychosis, really, really bad psychosis. And say I was trying to kill him or whatever. Or he would, you know, I mean I have to be honest with you, he’d smash a bottle and whatever and was trying to cut his wrists with it and jab it into his neck. I literally, you know, just try get the police, get the ambulance and whatever and get him off to A&E who would then look at him and go “Oh” and off to the mental health hospital. We sort of like was a little bit on this merry-go-round of he would go in and whatever, they’d adjust his tablets, he would say he was fine, whatever, be discharged. And then a couple weeks later going back into the same thing.

Interviewer: Oh god, [Name 4], it becomes multi-sectoral but not integrated, which is precisely what we don't want, many people involved but not talking to each other.

Respondent: Yeah.

Interviewer: So I mean, with the police and everything, do you know if the police had [Name 2] flagged up as a person with Huntington's disease?

Respondent: No. And again, this is where it was really difficult because a couple of times they [police] just wanted to take him to the station to a place of safety, which I was like “But that's completely inappropriate, he's got an illness, he's got a disease and that, why are you taking him to a place of safety rather than actually he needs to go to the hospital or we need some joined up thinking?” And again, and this is not about the individual officers, again, they tried their hardest but they weren't experts. And this is what I kept trying to say to social care and to the mental health team and whatever “Why are we constantly going this route? Why?”

[0:21:28]

And this is why I had to refuse to have him home, I can't expose my children to this. You know, it’s not right. I can't expose them to it, and don't get me wrong, I mean I was very lucky in the fact that my dad literally lived less than five minutes’ walk away. So if I could see him deteriorate, or if I could see he was going into psychosis and whatever, I would literally just send my girls round to my dad so they didn't see any of this, you know, and that. But you know, particularly mental health team, and they would just accuse me of exaggerating. I mean, one time I'd literally, you know, he'd been on home leave and that, you know. He'd been okay, been on home leave, I took him back to the hospital in the morning. He did not want to go. He really did not want to go. And I literally had to say again that [Name 2], you know, you are under a voluntary section at the moment. You need to go back, otherwise they're going to put you onto a section three and all of that and had treatment to get (inaudible 0:22:42) etc. Took him, managed to get him back and that, you know. Went out for a walk with my little girl because we need some fresh air, we need whatever. Went out and I got a phone call from my brother that he must have come out of the hospital, somebody left a door open, which they weren't supposed to do. Got on the bus and somehow and he was walking down the main road in our town and whatever with no shoes, just socks on and whatever. And he was literally walking down the main road, which is a really busy road.

And that again to me, this is how could this have happened? How could this have happened? And I actually, because I was trying to get at this point as well, continuing healthcare funding for him, I actually wanted him to be on a section three because then at least, you know what I mean, we could have got some continuing healthcare funding for him, but they would only have him on a section one or a section two. I think it's deliberate. I really do think that's deliberate, you know, so that they didn't then have to fund any support and whatever.

Interviewer: How did you ask for CHC? What was the process for you to…

Respondent: Yeah. Well, when they were going to discharge him, so I said he was in originally for two years and that was literally because I said I cannot have him coming home and that, you know, not while he’s undergoing psychosis, not all of this, I can't have him coming home. It's a safeguarding issue with having two children in the house because obviously both my girls were children at that point and that, so at one point they were going discharge him to a homeless hospice. That was it, you know. I mean, just like “You can't be serious.” And this is again, I was having meetings with the discharge matron, I was trying to have meetings with social care, the social workers and everything, but they thought that would be appropriate. And this is again, I'm like “Please, if you're not going to listen to me, please listen to the Huntington’s team or listen to the care advisor from the Huntington’s Association because you surely can see that that is an unsafe discharge.”

And again, this is why he ended up there for two years because health and social care were just arguing about who would fund it and tried to bully me having him home, and that was part of my complaint because I said they were breaking all safeguarding protocol about discharging somebody who was very mentally unstable and whatever into a home where there’s children.

Interviewer: So with so many people that knew of Huntington's, you know, with the expert team, with the Huntington's and his advisor, why do you think they were still, well?

Respondent: In all honesty, I think it was literally due to funding and I think it was the arrogance of the mental health trust that they really would not take advice from anybody and they knew better than everybody else. And even though it was Huntington’s, it was presenting itself as psychosis or disassociation and they knew better than everybody else and everything. But they gave him medication that he reacted badly to. And again, I was having to say “But it actually says on his notes that he can't take risperidone because he has a really bad reaction to it and it sends him into even more disassociation.” They didn't even read notes and everything. When you're in a secure mental health unit, I mean I've never experienced anything like it, however at times it was, you know, it's all about rehabilitation. So it's all about drugs, alcohol, sort of like rehabilitation and that which does not work with somebody with an organic disease.

[0:27:18]

Interviewer: Yeah, you didn't feel it was the right place for him? Yeah.

Respondent: It really, really wasn't at all. And I was thinking if I could get CHC funding at some point and that, you know, or whatever, then I've got more chance of getting them into a specialist residential home and that where he could have had more appropriate care. But yeah, I think it was deliberate that method because mental health care is all based upon rehabilitation, it's not based on deterioration. And I think that the problem is for me with people with Huntington’s being put in that sort of environment, so say for example, there was one time when there was a lot of people in self-harm, many self-harmers in there and like self-harm is like not even anything he’d ever thought about. But they were literally sitting in the day room talking about what was the best razor to use or what was the best thing to use to self-harm and whatever, so he started self-harming. And my argument would be because he wasn't in that situation; that thought would've never been in his head, so you know.

(Inaudible 28:32). Do you know what I mean? And I feel like mental health is very much this sort of poor relation of health and that. And in one way for me, I get annoyed when I keep hearing about awareness, awareness, awareness and it's like you’re saying with Huntington’s isn't it? Well that's great, you know, it's great that everybody's got awareness and we're trying to raise awareness of it, but actually that doesn't help people who are actually in there at being supported and that. And I think that sort of funding disparity and whatever it’s great that we raise awareness, but if there’s nothing there for these people afterwards, what’s the point? So it’s hard, isn’t it? So it really, really is hard.

Interviewer: So [Name 4], so what do you think would help then, you know? What would help?

Respondent: Yeah, I think for me, and again it really is, I can’t talk for the people who just got chorea and that, because I do feel that the people who tend to have chorea, you can automatically see that there's something wrong with them and people are far more understanding be that health teams whatever on that because they can see it. You can see it's like Parkinson's or whatever, you can literally see that. I think for me it's that far more joined up working and understanding of the mental health difficulties and the cognitive declines that can happen and that. And I have to be honest, I mean at one point I had children's social services investigating me and whatever because the hospital said he's made threats against the children, which wasn't true, but children's social services having to investigate. But having social services, you know, all of these different people and none of them have an understanding of Huntington’s. And I feel like for me that almost a willingness just to read about it, or actually talk to the person who's most involved with it so that they get an understanding of how it affects that particular person.

And then if I’m being brutally honest read notes (laughs). You know, read notes because I felt like it was all there. I’m an email queen and all of these people, doing the job I do as well, I always you know, if you have a meeting or a phone call I email back to say “This is what we've discussed and this is what we agreed.”

Interviewer: If it's not written, it didn't happen (laughs).

Respondent: Yes, absolutely. So I feel like that again, it is that integrated care; very personalised care as well. And again, I mean I work in [education and disabilities role] actually, but so we bang on about personalised education, personalised care plans and all of those sorts of things and I don't think it's rocket science in a way, I think it's quite an easy thing to do, but it can be so cost effective. Because the cost of keeping [Name 2] in an inappropriate position that actually made him worse for two years and then there was a break and then there was another year, but for three years out of seven he was in a mental health hospital. How on earth, how much has that cost? Again, this is what I feel with it, you know. Actually, if we get it right lower down it actually saves more intensive cost later on.

[0:32:39]

Interviewer: Yeah, that's what I think as well.

Respondent: Yeah. Yeah.

Interviewer: And who was particularly helpful through this management with [Name 2] through managing Huntington's?

Respondent: Sorry, the team at [Location 2] at that point had an occupational therapist and once she came out she was absolutely excellent and she tried to support him and that. And again, because one of the…when they discharge, sorry again, this is going back to the hospital. When they discharge part of what they say, they have an occupational therapy assessment to see how well they will cope and part of being able to cope is being able to put a pizza in a microwave. So they sign the discharge because they can put pizza in a microwave so they can feed themselves. And my argument with that is yes, he might be able to put the pizza in the microwave but he would be unable to go and buy it (laughs). He’d put it in, you know, and all of those sorts of things. And to be fair to [Name 5] the Huntington's occupational therapist, she worked really hard to make it a safe discharge and she then tried to come out into the community when he was out to maybe help him go on the trains, for example, and that and almost do like visuals and those sorts of things. So she was really good.

But again, I think the something was reduced or something or, you know, and actually yeah, he didn’t, I think she was…Sorry. I think it was about a year that she was really good but then she left and we never really got another one and that, so you know.

But also the regional care adviser, which they were at the time (laughs), Huntington’s adviser that [Name 6] at the HDA are really good because she was somebody who I could pick the phone up and go [Name 6], you’ll never believe what's happened now” and although she couldn't always help and that, you know, at least it was somebody who I could turn to.

Interviewer: You knew there was someone on the other side of the line, isn't it?

Respondent: Absolutely, absolutely. But she was really good. Yeah.

Interviewer: What do you think would have made a real difference, [Name 4]?

Respondent: I think for me, again, it’s that just understanding him and you know. I mean, you know, talking about suicide risk, things like that, because he was constantly threatening suicide and actually he did, well, we don't quite know because the coroner came to, I mean, when he died, the coroner couldn't come to a verdict whether it was suicide or it wasn't suicide, if that makes sense. So I feel when I was…there was the team that, you know, please do not put in any, you know. Please do not put him where’s he got ligature points or anything like that, but if they actually listened to me because at one point in the hospital…I mean, this is how ridiculous it was, at one point in the hospital they left a blood pressure machine in there. He literally took the leads off it and tried to hang himself with it. But that to me should have been done in the proper risk assessment. I don’t understand even to this day (inaudible 0:36:40) or anything like that, you know. But they left those sorts of things in his room, you know.

Interviewer: He wasn’t with a one-to-one when there's like a professional just?

[0:36:57]

Respondent: There was at some points. But again the problem, and this is…and I'm not going to whatever, but the problem that I think in secure units and things like that, they very clearly say to you “We're not here to prevent suicide. If people want to kill themselves they're going to do that” and that's quite hard to hear sometimes, you know, and that. And at some points you do have a one-to-one, but no disrespect, he was [measurement redacted], he wasn't a small man by any stretch of the imagination. And at one point they gave him an 18-year-old young lady who had no clue and actually it was unfair to put her in that position. And again, the staff turnover on some of these wards is just unbelievable really. And that's what I'm saying for me, I'd rather he have been in a care home but, effective, was both for mentally and physical health but also wasn't sort of like where there’s that turnover. With mental health this is what really frustrates me. A lot of the ward assistance and I get it and I do understand it in a way, but were previously actually, you know, (inaudible 0:38:23). And when you’ve got, you know, a ward of…I'm going to say there was 15 on it and when he first went in there, which was absolutely dreadful as well, you know. But they've only actually got a ward manager and a nurse and that and the rest of them are healthcare assistants, some of whom have been previously within that system. But there's no therapy. There’s nothing. There’s no activities, the activity coordinator left. But they have some colouring books in the day room. That was it. You know?

Interviewer: There's no real plan. There's no real plan for improvement.

Respondent: No, absolutely. Again, only because whatever, I mean I wasn't sure it was going to happen, I was like can we…but like psychologists, “Are we not gonna get these psychologists in here? Are we not gonna, you know, whatever?” And they have [n] local psychologists who literally all say it’s too complex for us, we can't help. And I was like “Well, why is he on a mental health unit then? Why? You’re literally just medicating and not doing any therapies or whatever with him, so what's the point of him being here? Why are you not going forward with social care, continuing healthcare building so that you can get him out into somewhere where, you know, and that he's going to be more appropriately supported?”

(Inaudible 0:40:01) he needed to come home, he needs to come home. You know, [Name 1 interviewer], I think the one thing that upset me the most, I literally have...so he was home one day and that, just on leave, it wasn't supposed to be whatever, you know, it was supposed to be a Friday to a Monday leave and whatever. The social worker came around on the Friday morning, he was like “Yeah, I'm fine, I'm fine. It's great. I want to be home, I don't want to go back there, whatever. It's great. It's great, it's great.” And then after half an hour chatting the social worker said to me, “Well, I think I’ll close this case because there's no need to be here. Whatever.” I’m like “No, no, no, no. Please don’t. You know, actually he's not right and whatever.” The social worker then said to him “You like being with [Name 4], don't you? You’re where you wanna be. You’re happy aren't you?” and he said “No, [Name 4]’s trying to kill me.” And he’d be “[Name 4]’s trying to kill me. I just want my girls. And [Name 4]’s trying to kill me, this morning she tried to knife me.”

And it was on, and then the social worker literally went “Oh, he’s fine and whatever. Don't worry [Name 2], [Name 4]’s not going to do that and whatever. I’ll close the case” And then he went to shake my hand, I went “I literally can't shake your hand. Please do not close this. I can't believe that you are leaving me with this and whatever because I'm not going to be able to get him back and whatever.” And again, later that night, again, he went into a massive psychosis and that so I ended up just calling the police.

So for me, again, it's just that believe the carers. Believe them because we do know the people better than anybody else and read the notes. But he was too complex for everybody. And I think again, that's the problem. So they minimalised it because then they didn't have to deal with it.

Interviewer: Oh [Name 4]. So, I mean, oh (sighs) I can’t…I mean, (sighs) and that's just a snapshot of the scene and it sounds like, you know, it just seems like a movie that it can't be real life like that that happened like that and she closed the case and left.

[0:42:29]

Respondent: Yeah, I totally agree. You know, I mean I feel like looking back I probably did have a bit of, you know, what's the word I'm looking for? (Inaudible 0:42:43) worked fulltime and that, you know. And I think I needed those distractions to get through it. I was only in my 40s or whatever, in early 50s. I think unfortunately if I'd have been in my 60s or my 70s, I really feel for carers who are older themselves because I had the energy, people who are older because you know.

Interviewer: (Inaudible 0:43:19) for example the social worker was [Name 2] always there or did you have time to speak openly? Just you with a professional?

Respondent: No, no, no. He [husband] was always…it’s not in his capacity and that, you know. And he said he doesn't, he doesn't want us to talk to you. I could never really talk in confidence to anybody, only to the HDA really. And again, like I say I tried my hardest, but it was really, you know, that for me was the most difficult part of it because I was giving them all this information and I was trying to…I'm even going to say not just do anything, just do the basic like proper risk assessments and personalised plans and whatever, medication and yet they didn’t speak to me. And he used to come out of psychosis and some days he would say “Please speak to [Name 4]. Phone her. I don’t know what I'm doing, phone her and whatever.” It was a busy ward, I'm not going to say…”But I want her at the ward round and whatever.” So I'd go in, but by that time he could have been back in psychosis. So then it would be “No, I don't want her here” and everything, you know. And I know that people can't work against the Capacity Act.

You know, and this is the thing and this is what I kept saying, you know when you feel like [Name 1 interviewer] you're being gas lit.

Interviewer: Yes.

Respondent: But I was actually saying I do understand the Capacity Act, I understand the declaration of liberty safeguards and all of that, but what I'm trying to ask you to do is to understand that I've also got a background in safeguarding, and what you are proposing is you're not safe.

Interviewer: You’re not the first person telling me that the Mental Capacity Act is actually not, well, it's being harmful in some cases and it's actually not working in favour of people with Huntington's disease interests. So it's interesting. So this was a conversation I had with a professional that's extremely knowledgeable of Huntington's and we were discussing that actually there's this loop, this crack that then people end up falling through and then this is what happens is that, well, but we need to follow his wishes because he has capacity. Well, does he?

Respondent: Yeah and you're absolutely right there. It's almost like saying that they've got capacity, but then they lack insight, isn't it? It's like those two are contradictory, isn't it? You know, you can’t have either he's got capacity and he's got insight or he hasn't got capacity, he hasn't got insight. So you can't have that both ways, but you know.

Interviewer: Capacity depends on the things we're discussing and it fluctuates. So I wonder if there's an issue with people that are assessing capacity, actually not understanding, you know.

Respondent: I agree.

Respondent: And again, it's like I kept saying at the end of the day, people can go in and out of capacity. So if you have capacity two weeks ago, that doesn’t mean anything for today and that, you know. I think for me, because I sort of like work on a periphery of this sort of thing a little bit, I think what really used to upset me is where I was having them and then they was arguing with me and gas lighting me. Well no but it’s the law. It is the law but you are wrong and then I was, it was written all over his notes, which is one of the things I challenged actually with the complaint, that I was a challenging person and I made people feel uncomfortable. I was never impolite, I never raised my voice, you know.

[0:47:57]

But what I would do, and again this came out in the complaint, but what I would do was respectfully challenge people where they were wrong and that, you know. I got (inaudible 0:48:08) and I was absolutely exonerated that I wasn't. And I feel like again, for me as well, and generally the poor care, people get fairly defensive, they close ranks (laughs) and perhaps not honest about why mistakes have been made. And you know, we all make mistakes. We’re not human if we're not making mistakes. And I always see complaints as learning and I just didn't understand why they ended up attacking me rather than thinking “Could we have done this differently?” They could think that and then come to the conclusion that maybe they couldn't have done it differently. But that's fine because at least they examined their practices and that, you know. Like I said, I wasn't unreasonable but I just feel, you know, and in one way you know where you’ve sort of like got peer support, so I was in communication with a lady in [different county], which is quite a way away from me, but who was going through very similar circumstance with her husband, who was being held in mental health rather than physical and that sort of thing and there was no joined up thinking and that. So I mean, I'm a really good believer in peer support, if that makes sense. But equally sometimes when everybody's in the same boat it just ends up being even more traumatic.

Interviewer: Yes, It can sink you more, isn't it? It's just heavier if everyone is on the same boat especially there's a hole and there's water coming in. So the more people it just weighs more.

Respondent: Yeah, you're right, you're right [Name 1 interviewer] so yeah. But it's great to share but for me I just think what was really shocking is that lack of risk assessments and things like that, that lack of understanding of a whole person and the complexity of Huntington’s. And I actually do believe if he had lots of chorea, it would've been different.

Interviewer: Yeah, I think it's more visual isn't it? People seem to have more empathetic, there's less space for arguing, I guess.

Respondent: Absolutely. Absolutely. Yes,

Interviewer: [Name 4]. So if I ask you to picture that [Name 2]'s care was excellent, what would you picture, how would you picture this? That his care was excellent and that you have a better experience what would’ve that looked like?

Respondent: I think for me what I would think is that I think there should be more neurologists and that, so even if they're not specialists in Huntington’s and that but there should be more neurologists who would be happy to take advice from the more specialist teams and that, you know. That when it is something like Huntington's or MS, Parkinson's, etc. that where it is a mental health issue that actually they don't end up into mental health, they end up onto neurology and then there's far more of an understanding of disease of the brain and that, you know. And then I think the social care, and again when people with Huntington's need social care input that again that there's perhaps specialist social workers who work alongside neurology rather than being general social workers, if that makes sense. And maybe in that type, you know, more of an all-age social work potentially specialist, if that makes sense; that can also across children’s and adult services. Because I mean for me it always felt that my girls were the last people that they thought about and that, you know, rather…Do you see what I’m trying to say? I’m probably not very well…

Interviewer: No, you should because as you're saying, it's like they just focus on what's right in front of them and it's a condition that was affecting your whole family, your whole household and your children had such a different age from the adults that you really needed someone to be able to explain how to explain certain things at children's levels, or how to protect them the best way possible. Was that it? Did I get it right from?

[0:53:32]

Respondent: Absolutely. Thank you, [Name 1 interviewer], yeah. Thank you.

Interviewer: Yeah, so you say you explained it very well. Okay. Alright, so more neurologists and a social care worker with some specialty, I mean maybe not Huntington's as a specific but with this level of knowledge of physical and mental health bridge, I guess, yeah.

Respondent: Yeah, more neurological I suppose. I think that for me, if I've had that social worker that even have some understanding of dementia that would've helped. So maybe more neurological organic disease type of knowledge and that and everything. But we got put into, well, [Name 2] got put into again the DSM classifications, so [Name 2] got put into psychosis, FM, which then there are them sort of like local social work service was then only given to a person who, you know, have experience with psychosis and that, you know, and again just no understanding of knowledge of Huntington's whatsoever or any other neurological issues. So even if they had an understanding of dementia it wouldn't have been so bad, but they didn't and that so because they were very much psychosis.

Interviewer: Yeah. I’m sorry if you hear a noise on the background it’s my puppy going crazy for some reason, he’s just gone wild. Sorry. It's him ruffling on the bed (laughs). Okay, sorry about that. Okay, I did understand. So they had this experience of psychosis. I'm sorry, I can't even…can you stop it? I can't hear. Talking to a dog like if you understand what I'm saying. So they have an understanding of psychosis but not from organic conditions like Huntington's disease. So you were saying that even if they, you know, an idea of dementia. Do you think dementia gets more sympathy somehow?

Respondent: Yes I do because you know I feel like people have got more understanding and there’s dementia cafes and things like that now. And I think I should probably just explain [Name 1 interviewer], because [Name 2] was put into DSM category of psychosis, the way the social work works within [Location 4], okay, if they've got a mental health like DFM justification, they only get social workers that are mental health social workers. They don't get general social workers and that because the way they want to prove it they have a board in between the ICB and the mental health trust, which is completely different to the physical health trust, which is the other problem. We've got about three different trusts working within [Location 4] and that, you know, they’re all split and do different things. So once you get a DFM classification you will only get a social worker that's mental health. So they would never even deal with people who do trips and falls necessarily, it's only about mental health. So again, I think was another problem and I do feel for me that, you know, neurological would be better if you are going to split social working for very specific things then, you know, for me Huntington’s and those sorts of ones, dementia, should be under a neurological team rather than a mental health team.

Interviewer: Okay. Yeah, it's almost like you need to fit into their boxes. You can either be mental or you can either be physical, can’t be both.

Respondent: You can't be both. It's not for me, but I think the where I completely truth on this because actually I understand how the different trusts work. I understand the ICBs or clinical commissioning groups as they were there. I don't want this to sound the wrong way, but I probably understood more than them because I did it for my work, I do it from a very holistic way and that, so you know. But I don't think they've really had anybody was challenging them before on things like the Mental Capacity Act. But I actually did know what I was talking about so and I think that's what they really struggled with.

Interviewer: That's why you were classified as difficult.

Respondent: Yeah, 100%. Yeah.

Interviewer: Okay, [Name 4]. Alright, I'm going to do a couple of generic questions.

[redacted]

[End of Transcript]