[0:00:00]

[redacted]

Interviewer: Okay, good. Okay, so can I start by asking you what’s been your experience with Huntington’s Disease?

Respondent: Yeah, so it’s my dad who’s currently has Huntington’s. I was made aware about two years ago, he had symptoms and he was tested quite a while back through, and I’ve sort of been his part-time carer, trying to get him access to accommodation, certain healthcare aspects, over the past few years. My relation to it as well is I’m not gene-positive, but I haven’t been tested, so I’m just at risk.

Interviewer: Okay, not just at risk, you’re at risk, which is a status, per se. So you’ve only…so you say two years ago you were made aware of his diagnosis when he started having symptoms, can I ask what sort of symptoms was he having?

Respondent: So just a lot more obvious dementia symptoms, a lot more chorea, yeah, I think it just started to become more of an issue with housing and his life and his work and…and it’s progressed quite quickly over the past two years since then.

Interviewer: He’s not working anymore.

Respondent: No, no. He’s, yeah, we’re looking at sort of centring him to a more complex specialist care home, as he’s in sheltered accommodation right now, with external carers coming in, but there’s no live-in care.

Interviewer: Okay. So he has external carers coming in from, like, a private company.

Respondent: Yeah, that’s funded by the hospital, just three times a day.

Interviewer: Okay, but you find that he needs more supervision?

Respondent: Yeah, I think he needs live-in care at this point, just in case he refuses medication or refuses food or personal care when the carers have their allocated timeslots, and there’s a lot of angry outbursts and frustration, so he needs to be around staff that are trained to a higher standard and prepared for Huntington’s patients.

Interviewer: So these carers coming in at the moment, are they not trained for Huntington’s?

Respondent: No, it’s more care for elderly patients who just need hep moving around, it’s not a lot of, like, training for psychological issues, it’s just more physical. We’ve been through three different care companies in the past six months, because he’s been aggressive because of the Huntington’s, then the past two have left, and refused to go back onto the premises, so it’s unsustainable.

Interviewer: So who helped you find these care companies, if anyone?

[00:04:02]

Respondent: Yeah, so our main point of contact in terms of who helps us is just [name 1] at the Huntington’s Disease Association, she’s the regional advisor for the [geographical area]. Yeah, she got in contact with the social worker, the hospital social worker was the first person to refer us to care companies, but the HDA advisor has sort of helped things move a little faster, you know, by calling up and pushing services to move us up the waiting list.

Interviewer: So why was your dad in hospital?

Respondent: So he had a fall at the beginning of summer last year, and then he was in hospital just because of the fall, and then they found out he had pneumonia and he had a type 2 MI while in hospital, so it was prolonged, he was there for four or five weeks, partially in ICU, and then partially just in the departure lounge, waiting until a care company could be provided for him. And after being in hospital for so long, he had a lot of muscle wasting, and lost his mobility so he wasn’t able to walk for several months afterwards, and, yeah, so he wasn’t legally allowed to leave the hospital because his condition declined so much during that time, that he legally needed carers to come into his flat. So the hospital social worker organised that, and that was the three care companies that we’ve had since then.

Interviewer: Okay, so I mean, the advisor is trying to push through with the social worker to get companies.

Respondent: Yeah.

Interviewer: Is she suggesting, like, which companies, the social worker, because it sounds like the companies that you’ve had so far have been a bit caught off-guard with his mental health side?

Respondent: Yeah, yes, definitely. [Name 2] from HDA provided training, but it was only brief, just like a half an hour session for one of the care providers on Huntington’s, but yeah, it is quite hard when they’re changing so frequently, to provide that external training.

Interviewer: Yeah.

Respondent: For some carers, it was, yeah, the first person with Huntington’s that they’d met.

Interviewer: Yeah, it’s not really a half an hour training that they’re… But as you’re saying, even if they were to do a two day course, then it just might be that with the rotation of people, it’s quite hard to keep people trained.

Respondent: Yeah, exactly, yeah, because there’s always…you can’t predict how big a team’s going to be, and when there’s new staff being added constantly.

Interviewer: And so you’re trying to move him to a more complex care, like a more long-term care setting.

Respondent: There’s two care homes within an hour radius of where I am, and that have Huntington’s wards, so a corridor of about 10 people with Huntington’s in that section of the care home, and so we’re looking at those kind of places where everyone’s trained fully.

Interviewer: And these have been advised by [name 1]?

Respondent: Yes, it has, she sent us a list of care homes to look at, but the only barrier now is we don’t have council funding, because they’re, like, 10 times the price of most sheltered accommodation, it’s quite expensive for specialist care homes, so we’re waiting on council funding, which will be good, because we need to have an assessment from a community social work team, so we just need to wait for that, but they haven’t picked up his case yet. It’s a big gap in resources, where he’s left without a social worker, so we can’t access funding and we can’t move to the next step.

[00:08:34]

Interviewer: So when your dad went to this temporary situation, so the social worker was trying to find a company that would go to him, and then once the company was found, the social worker stopped engaging with the family? He was discharged or…?

Respondent: Yeah, so it’s because we had a hospital social worker for longer than is meant to be had, so the hospital social worker, she’s called [name 3], she’s been, yeah, she’s the main point of contact for a lot of, like, finding new care homes and stuff and referring us for stuff, but she wasn’t meant to be working my dad’s case, it was meant to be transferred to the community social work team, which are outside of the hospital. It was meant to be transferred months ago and no-one’s picked up his case, so she’s just sort of been doing overtime, but she’s been forced to leave his case now by her manager’s, because he’s not been in hospital for months. I hope that’s clear.

Interviewer: Yeah, yeah, of course, I mean, it should be a win-win being able to keep him out of hospital safely. Okay, so how long have you been waiting for the community social work team to be involved?

Respondent: They should have been involved since, yeah, it was June that he left hospital, last June, or the end of that month, so it’s been quite a few months. He was referred again about three weeks ago by the hospital social worker, just handing off his case, that’s when she left it fully.

Interviewer: And they didn’t have any prediction of when they could come around or…? I mean, did they say anything or…?

Respondent: No, we’re usually sort of left in the dark with that kind of stuff, like when we’re put on wait lists, there’s no real gauge of how long it could be, it’s just sort of…you’re left without contact for a while. So we’ve been left…it’s only been three weeks so far that we’ve not had any social worker, but we should have had the community social work team several months ago, and the hospital social worker shouldn’t have been helping us for so long, it’s just…

Interviewer: Well yeah, it sounds like she was being protective of your father and you, very rightly so, but going beyond her remit, yeah.

Respondent: Yeah, and it was very kind of her.

Interviewer: Okay. That’s really not ideal. Yeah, but that just…another reflection of the issues happening around care.

Respondent: Yeah, it is, there is a massive lack of social workers in this area, it’s just part of the normal, like, it’s just normal now, expected, it’s not shocking anymore, which is quite upsetting.

Interviewer: Yeah. Do you have anyone else in your family involved with your dad’s care?

Respondent: Yeah, it’s just me and my older sister. But we both have other commitments, so it is, we both try and share the responsibility when one of us is working, you know, we try and split it that way.

Interviewer: Yeah, I can imagine. Okay. And what about you, you know, as an individual, in your situation, so you found out two years ago that you were at risk as well, I mean, I’m not sure how long it takes for it to move from your dad’s diagnosis to realising that it puts you at risk as well? But were you offered any support or what happened with you?

Respondent: So my dad was diagnosed when I was a child, but I wasn’t made aware of that, and I don’t think I was approached at that time, because yeah, nobody in my family told me about Huntington’s being in the family. But two years ago, my sister just told me, because she was living in [location 1] and I was at university away from here, so she told me that dad had Huntington’s and then I went away and just researched it myself and found out what the symptoms were like, what it would be like, that I was at risk. I had support from my friends, but I didn’t have any, like, healthcare services to support me, but I’ve not reached out to be tested. So yeah, I think I have the option of going to genetic counselling and getting support that way, but I’ve just put it off for now.

[00:14:19]

Interviewer: Okay, does your…I mean, have you told the GP, for example, would the GP know that you were at risk?

Respondent: I don’t think the GP would have access to that information, because well, I’ve not talked to any healthcare professionals about it and I don’t think it would be linked from my dad’s medical info to me, I don’t think that…

Interviewer: How would you feel if that was the case, if, you know, because your dad was diagnosed, that it would be in your medical file that you are at risk, that the GP could see that you are at risk?

Respondent: I think it would have benefits and downsides. I’ve been informed before that being at risk, it increases your life insurance costs by three times, and if you’re positive, it increases it a lot more, so it also can affect your likelihood to get a visa in different countries.

Interviewer: Likelihood of getting what, sorry?

Respondent: Of getting a visa.

Interviewer: Oh, a visa, okay.

Respondent: Because of the healthcare costs that you’d eventually bring along with being gene-positive. So if that was the case, that would be quite upsetting to have that choice to test taken away from me, if it was on my file but it was just linked to my family, yeah. But it would be easier in taking up that extra step for people who are at risk, so the GPs can just offer support for people without being asked. It might make it a bit more accessible.

Interviewer: Okay, so I mean, I hadn’t…I didn’t have it in my mind that because you are at risk, it would affect your insurance, but I also don’t know enough about it to say that it’s not right. So basically, I can see, well, I don’t think that companies, like, insurance companies can access your medical records without permission.

Respondent: Yeah, it’s if you willingly give the information.

Interviewer: But I understand why that would, you know, the concern and that’s something, like, because you know, in my mind, I was thinking when someone’s at risk, and of course, it’s your decision to get tested, and if you’re negative, even if you’re negative…I mean, for me, it raises, as you were saying, about the support, because as you’re saying, you’re a part-time carer to your dad, for example, it could be that you could benefit from a check up now and then, to see how you are. So with a system being more proactive, making sure your needs are being met as well, so that’s where I was coming from, sort of instead of waiting for you to ask for help or schedule an appointment, that they could ring you one day and say, “How have you been coping? Is there anything you need from us?”

Respondent: Yeah, that side of things sounds really beneficial. I’ve definitely interacted less with the GP for my own health in the past year and a half, because I’m quite, like, I’m constantly going to the pharmacy and the doctor on behalf of my dad, that I’m a bit exhausted from it. I have neglected my own healthcare due to being a carer, like, so having the system integrated that way does sound good, it does take that extra step off the person who’s doing…

Interviewer: Yeah, because that was where I was coming from, because I do get that as a carer, you’re committed to your dad’s care and that’s your goal, making sure you’re doing the best for him, and as you’re saying then, your own health gets neglected.

[00:18:42]

Respondent: Yeah, definitely.

Interviewer: I don’t think people have the ability or the headspace that when they’re already so busy with, you know, you have this lens, you know, you have this tunnel vision into looking after a third person, so yeah, that’s why I was asking you about the GP records saying you’re at risk.

Respondent: It’s definitely the tunnel vision.

Interviewer: Yeah, well, you know, yeah, it’s normal, but then what happens is what you find is your health may get affected. I’m not saying it will, but it’s about making sure that you have someone around that can signal if you do need support, that it doesn’t depend just on you giving that step. But you know, as you’re saying, you do have a sister as well, and you’re in contact with each other, so it doesn’t have to be all health services, but not everyone has a sister or a brother, so, yeah, that’s…

Respondent: Yeah, I definitely think being a carer with no external support…it would be even more difficult.

Interviewer: So at the moment, for yourself, you’re not accessing any services or teams, you’re focused on your dad’s wellbeing?

Respondent: Yeah, currently. I used to be engaged wit the youth service run by HDA, I had a few calls with their youth advisor, and that’s anything up until you’re 25, so yeah, last year I used that quite a bit. So I attended the in-person events. That was more when I was struggling with processing the information in the first year of finding out that he had Huntington’s, and now it’s just…I need less specific support, currently I’m just getting on with doing his admin and yeah, coming to terms with being gene-positive.

Interviewer: Yeah, I mean, how do you feel about…you’re only able to access that until you’re 25?

Respondent: I mean, there is other services, it’s, yeah, not great that there’s such a hard cutoff point, especially because I found out about it when I was [20-25].

Interviewer: Yeah.

Respondent: But I think there’s still a lot of services available run by HDA for all ages, and it’s good that they’re prioritising their funding of services, so you know, for children and teenagers as well, because it would be quite hard being a carer and being in school.

Interviewer: Yeah, so from this age, have you ever attended any support group for carers, or…?

Respondent: I think they have monthly support groups across the country, and it just changes location each month, so I went to one when it was in [location 1] and it was okay, it was quite nice to talk to other people who are going through similar situations, because the first year was isolating in terms of talking to people about it and then having to explain what Huntington’s was, over and over again, and not having just a mutual understanding. But yeah, I’ve not been to the support groups regularly.

Interviewer: Why not? You feel you don’t need it at the moment?

Respondent: More just it’s not in a set location, so I’d have to drive quite far and I’ve just got other priorities, there’s just not enough time or energy whenever it’s on.

Interviewer: Yeah, I understand. Are you working or studying? What is it that you do?

Respondent: Yeah, I’m currently looking for a different job, I was working part-time, caring part-time last month, and then I quit because the job just got a bit too overwhelming with organising a lot of healthcare stuff. It just kept clashing at the wrong times and I needed to go for appointments with my dad, but I needed to be at work and then, yeah, calling in sick last minute to go to district nurse appointments just didn’t work out.

[00:24:07]

Interviewer: Okay, so you’re looking for a job now.

Respondent: Yeah.

Interviewer: Okay, well it’s, yeah, I’m sorry for that, because as you’re saying, it’s almost like caring is a full time job, so how do you keep both jobs, yeah.

Respondent: Yeah, I had to sort of, like, separate it emotionally because you have to prioritise your job while you’re there, but you’d be getting phone calls from the GP or the nurse or someone with important information and you either have to ignore it or, yeah, take time out of your work. Yeah, it’s been quite hard to find a job that’s compatible with care needs.

Interviewer: Was your employer, I mean, or your manager aware that you needed, that you had these extra responsibilities in your life?

Respondent: Yeah, they were made aware of it, but it was still quite difficult to manage all of these phone calls and organise stuff during work hours, and it wasn’t okay to, yeah, leave while on shift. There was a little bit of understanding but not to the full extent that I could, you know, do both jobs well, like, be a carer and do that job fully.

Interviewer: Yeah, okay, I’m sorry for that, as I said, it’s…

Respondent: Yeah, it’s a bit of trial and error.

Interviewer: Yeah, I mean, how is the job search going now?

Respondent: I’m just not too sure what is compatible with working hours, because the care needs can fluctuate so much, and until he’s in a care home, I feel like I need to be on call most days. Because sometimes we do have short notice of appointments, it can be within a day, a couple of days, so I need to be available the day after and obviously work scheduling is…

Interviewer: What appointments are these that come at such short notice?

Respondent: So before, we needed a lot of help with the district nurse and urologist as he had a catheter after leaving hospital, and then there’ve also been physiotherapists that have come by, speech therapists, doing the SALT assessment, I have to get pharmacy deliveries, if the medication can’t be delivered that week. Social workers sometimes come by to do assessments too, so they don’t really have much availability, so when a social worker does set a day, I really need to attend. Yeah, just that kind of thing.

Interviewer: And they all come one by one?

Respondent: Sometimes together, but it’s usually individually, yes.

Interviewer: Yeah, that’s what I mean, sorry, one by one, as in just…

Respondent: Yeah, [name 1], the HDA advisor is the only person who would (inaudible 00:27:32) the GP and the social workers.

Interviewer: Sorry, [name 2], I’m struggling to hear you now, I don’t know what has changed. I can hear you back on, so I heard you saying only with the HDA advisor, and then I couldn’t…

Respondent: She’s the only one who would attend appointments with other people, so she comes to advise the GP and the physiotherapist and the social workers, but that’s the only person.

[00:28:10]

Interviewer: Okay, that would be the only…and this advisor would be always the same advisor.

Respondent: Yeah, there’s only one person for the entirely of [large geographical area], it’s just [name 1].

Interviewer: And with the other ones, like, for example, if the physio comes, is it always the same physio?

Respondent: It was at the time, yeah, and they’ve stopped his care now, and it was just for a few weeks after hospital to regain some mobility, but it was the same two people, it might be, you know, one or two of them.

Interviewer: Okay. And with the social workers coming, I mean, you’re already using plural, so does that mean different people come, or is it because people come together?

Respondent: They come individually. He had a social worker assigned to him at the start of last year, but it was…it was meant to be the same person coming several times, but they closed his case, so they only visited twice, but that was the same person twice.

Interviewer: Okay. And why did they close his case?

Respondent: They believed he was in a stable enough position to not need care anymore, which was completely wrong, they just asked him questions and took his answers word for word, so when they asked him if he was able to take care of himself, make his own meals, be independent that way, he said yes, because he believed it. But he was at that stage…

Interviewer: Were you in these appointments or was he by himself?

Respondent: No, so we weren’t made aware of it, and sometimes the appointments, they just go straight to a system and don’t contact my sister or I, so when that happens, there’s usually a bit of misinformation because we can’t clarify what the situation is like all the time.

Interviewer: When he was discharged, was this decision challenged? Did anyone come back to social services to say, “Of course he said everything was fine, but it’s not”?

Respondent: Yeah, we’re always trying to gain access to more care, but it’s quite difficult to convince people, like, once the case has been closed, you know, you go back onto another wait list for several months, and you don’t really hear back. I think he ended up going to hospital while we were still waiting for another social worker, so then he got access to the hospital social worker while we were trying to get social care.

Interviewer: Was this due to the fall he had?

Respondent: Yeah. Yes, from that incident.

Interviewer: Okay. So what would help, [name 2]? What would help manage care or get proper care?

Respondent: I think just having all of the services being connected, so instead of it being entirely on family to make phone calls and relay information back and forth constantly, just having an online database so anyone who’s in the NHS can see where the person is at, you know, what needs are being met, what needs to be done, what wait lists they’re on, just having it more integrated in that sense.

Interviewer: Okay, so having all services accessing the same, like, software, the same information/

Respondent: Yes, yes.

[00:32:21]

Interviewer: Okay.

Respondent: You just spend a lot of time being on hold and yes, calling a lot of people and repeating yourself. Yeah, I think it would just streamline the services a lot better.

Interviewer: Yeah, so ideally, like, just to make sure to get the picture of what you’re saying, like, to have your dad’s care plan and whoever is involved discriminated and every time there’s a review, the information about the review is there, accessible, so that, for example, if the social worker comes and asks your dad some questions, that she knows that, for example, due to the condition, he will always say that he doesn’t need help and that he does everything by himself, so that, well, he or she understands that it’s not the case, or that actually, the physiotherapist came yesterday and he couldn’t transfer from the chair to the bed, just to put some context into it, basically. So you find yourself saying, “Well, last week we were visited by x/y/z, and on their assessments, this is what they said,” so you’re having to repeat a lot of the information.

Respondent: Yeah, and sometimes each service has different levels of information, so they think things are okay because they have an update from several months back, and it’s not really the case, so it is quite disjointed between everyone, like the GPs have different opinions from social workers a lot of the time, and sort of refuse to work together when there’s, like, a lack of care, so when social workers aren’t available, the GP can do similar tasks that need doing, so in terms of the continuing healthcare checklist, both the GP and the social worker can do them, but his GP has refused to do it in the past because out of principle, the social worker should be doing it.

Interviewer: So a hot potato.

Respondent: Yeah, yeah, it is a lot of people just sort of pushing along another job to someone else to do, and just, yeah, passing the case around, and it does waste a lot of time.

Interviewer: Okay. So okay, so do you…what do you go to the GP for in terms of your dad’s care, what is it that you need him for?

Respondent: So currently, we ask to get the continuing healthcare checklist resolved by them. They also do a lot of blood tests and blood pressure tests, just to keep on top of his medication needs, so that’s quite regularly. He’s had a lot of interactions with the urologist and district nurses, yeah, his catheter was taken out about three months ago, but up until then, that was the main reason we were going to the GP or the GP was coming to him, because it kept getting blocked, he couldn’t pass urine for, like, 24 hours, so there was just a lot of frequent visits for that. Yeah, he had some contact with the neurologist at the larger hospital nearby, but that’s every few months, like, every nine months, not very…it’s quite hard to get appointments with her.

Interviewer: Every nine months he has a review in the neurologist?

Respondent: Yeah, I’m just saying that as a general, like, vague estimate, I can’t remember, we’ve only had two appointments with the neurologist, they’ve been quite spread out.

Interviewer: Was this at the hospital?

Respondent: That was at hospital, yeah.

Interviewer: So you take him?

Respondent: Yeah, yeah.

[00:36:46]

Interviewer: You or your sister?

Respondent: Yeah, we both take him and then get a wheelchair from the hospital to be able to make it to the appointment.

Interviewer: And do you find these appointments with the neurologist helpful?

Respondent: No, well, honestly, it was quite distressing for him and not much came out of it in terms of help. And the second one had to be over the phone because he wasn’t able to make it into hospital the second time round, and that one wasn’t very useful because he can’t really have over-the-phone appointments, and interact with the doctors very well, like, he can’t keep up with quite long sentences and a lot of new information being given.

Interviewer: When this phone appointment was organised, was it with you or your sister as well, or was it just your father?

Respondent: Yes, it was with me and my sister over the phone, but it was just…it was cut short a lot and there was a lot of the doctor sort of talking over us and, yeah, it wasn’t very productive. Nothing came out of it.

Interviewer: So who takes responsibility for your dad’s treatment?

Respondent: Could you clarify what kind of treatment you mean?

Interviewer: Yeah, so I mean, we know there’s no cure for Huntington’s, but depending on whatever symptoms your dad has, there are different treatments, and his disease will progress, so I’m asking who medicates him, who decides if he needs speech and language therapy, or if he needs an occupational therapist, who takes charge of his care?

Respondent: Gosh, it’s not really one person. So the neurologist prescribed olanzapine for him on the first appointment they had, but she hasn’t really got continuous treatment, it’s just sort of been, you know, prescribe that medication a year and a half ago, and that’s it. Actually, it was [name 1] the HDA advisor who helped to get in contact with the physiotherapist and the speech therapist, that was meant to be the social workers, but it wasn’t getting done, so the HDA advisor organised that. And then the GP has prescribed all the other medications, a few were prescribed in hospital when he was staying there, and then a few have been prescribed gradually afterwards, just, he had a few home visits from the local GP and they’ve put him on different medication for blood pressure and iron and stuff. But it’s not cohesive, no-one’s really assessing his entire list of medications and seeing that they don’t interact badly, its’ more just, you know, everyone’s chipping in a bit but there’s no one person following his healthcare.

Interviewer: Would it be helpful to have someone?

Respondent: Definitely, definitely, we need someone like that, it’s just not available. And it’s quite sad because there’s no-one who knows him and sees the progression of his disease, so everyone who’s treating him is treating him from that one point of view, how he is that week, not the big picture.

Interviewer: From all the professionals you’re in contact with, which one would you say knows your father the best?

Respondent: [Name 1] the HDA advisor. She’s been the only consistent person for the past two years.

Interviewer: There’s no specialist nurse around there?

Respondent: No, no, it’s been hard enough getting a district nurse to come out when there’s a medical emergency, let alone, you know, when things are not terrible.

[00:41:29]

Interviewer: Okay.

Respondent: It’s a lot of one off interactions.

Interviewer: Okay. Is there anything that you are happy about how it’s going, in terms of, like, anything that works well?

Respondent: I’m really happy that the HDA advisor is proactive, like, she does check in from time to time and ask if there’s anything else she can do and points in the right direction, so we can keep making progress. But yeah, that’s obviously the only service that is sort of going smoothly. I’ve made a list of all the services that he’s been in contact with or in use with, if you want me to read out each person that’s been involved in his care this year.

Interviewer: Yeah.

Respondent: Yeah? So I’ve got the district nurses, the urologist, external care providers, HDA advisor, hospital social workers, community social work team, the housing manager, the housing staff, as they need to do a lot of his laundry daily due to his incontinence, the GP, pharmacy delivery, neurologist, physiotherapist, speech therapist and occupational therapist are all the people that we have to sort of pass information between. I’m probably missing a few, but those are the main people that are involved in his care, yeah.

Interviewer: Yeah, that’s quite a lot of people for you to look after.

Respondent: Yeah, it just builds and builds and there’s a lot of phone calls to keep track of.

Interviewer: And with the CHC application, is it [name 1] helped you with that, or is anyone, I mean…?

Respondent: Yeah, [name 1] has emailed the GP with, like, reasoning of why he’s…would trigger the checklist for higher funding, but yeah, we’re just sort of waiting for someone to pick up the case for it to move further.

Interviewer: I mean, in the current house that he’s in, like, with a housing manager, are they complaining?

Respondent: Yeah, that’s why we’re looking for somewhere else, she’s actually considering an eviction notice because of the aggression and there have been several incidents where he’s thrown things at staff, and been abusive, that it’s just gotten to a point that they’re no longer able to have him there.

Interviewer: When was his last neurologist appointment, do you remember?

Respondent: Last year, a long time ago, I couldn’t remember, yeah.

Interviewer: So in this situation, for example, could you ring the neurologist, the secretary and say that your father is having his aggression situations, that he is making it difficult with his current carers?

Respondent: I could, but I don’t expect a response from that. They do seem very oversubscribed, that it’s quite hard to get in contact with them, like, I don’t have a direct phone number or email address, so I could put in a referral with the GP to refer in for another neurology appointment, but that would be in six months, a year maybe, and it might be over the phone and it might just be a dead end, so I’ve sort of been redirecting my energy to things that I know are going to work, so being more involved in HDA, and, yeah…

[00:45:50]

Interviewer: Yeah, you don’t want to run just to get tired, you actually want to feel you’re getting somewhere.

Respondent: Yeah.

Interviewer: And he’s not under any mental health team?

Respondent: No, actually, we tried to get him under the mental health team, in case he did get evicted within 24 hours’ notice, he would need, like, a private room in a hospital and that would be his only option to go, we’d have to go to hospital if he got evicted, and then he’d have access to a care home. But the mental health team reviewed his case and decided it wasn’t…he didn’t actually need any assistance, which, yeah, you can’t really argue with them.

Interviewer: It would be a joke if it wasn’t real, right, but…

Respondent: Yeah, I find a lot of this stuff funny, but then I realise it’s actually real, like, it’s got to a certain point where it’s not surprising, but yeah, the mental health team, they were contacted about two or three weeks ago when we first heard about the eviction notice, and yeah… it’s always because if it’s not an emergency in the moment, then they won’t come out, even if it had been an emergency a few days before. Yeah, it doesn’t really make much sense, h ow the system works.

Interviewer: It sounds like there’s nothing that needs to be done until a crisis happens.

Respondent: That’s definitely the experience we’ve been having for the past year, sort of running in circles, not being able to access care until there is a crisis, and then we get all the care, and then we’re sort of left alone again after, yeah, after it’s happened.

Interviewer: It’s not a great principle to work, I think.

Respondent: Yeah, we need to access the care when things are not in crisis mode.

Interviewer: Yeah. You don’t wait to go shopping, you don’t wait for the hunger to come and then go shopping, you want to have the food for when you’re hungry, right?

Respondent: I know, I think it’s just a lack of staff, they have to prioritise life and death, like, whoever’s in the worst, worst possible situation is given help and then people who are about to get worse, you know, the care has to wait because there’s no-one else there.

Interviewer: So if I ask you to imagine your dad’s care picture, something to say, “Oh, this is excellent,” what would it look like?

Respondent: Is this, like, reality or ideal care situation?

Interviewer: Ideal, ideal care situation, yeah. “My dad’s care is excellent…”

Respondent: It would be excellent if he had live-in care, to access the care 24 hours a day, so it doesn’t have to be forced upon him when he’s not able to process it, if he’s in a bad mood or yeah, people can come back to him when he’s able to receive it. Just having understanding and patience and kindness. I feel like there’s a lot of hostility with people trying to be caring for him because when he gets aggressive, it seems like other people get aggressive, and it just makes the situation worse, so it would be ideal if all the carers, like, everyone involved in the care understand Huntington’s fully and doesn’t, it doesn’t make it worse, it doesn’t make the situation worse by increasing frustration on his behalf. Yeah, just…yeah.

Interviewer: Okay.

Respondent: I was just thinking if he had more support with going outside more, it would be a big help with his mental health, just being assisted to go outside, because he’s not really able to leave his flat independently, and the carers just…currently they just go in for food and medication, and personal care. But it would be nice if there’s more enjoyable things done with him, like going for walks, going to the park or somewhere or other, just more activities like that, that are not just going to the hospital and, you know, things that you need to live.

[00:50:50]

Interviewer: Yeah, I think that sounds good, especially if he does have live-in carers, it should…they should be able to do that, right, because they’re living with him, they also don’t want to be in the house 24/7, “Let’s go grab a movie,” or…

Respondent: Yeah, definitely, it seems doable, like, the care homes that I’ve looked around, they do seem suitable to meet his care needs, but it’s just not accessible and we probably won’t get the funding for a while, and there is a lot of barriers in that way, so it doesn’t seem likely for…but I’ve seen that it does exist in reality, it’s just more likely if you go private.

Interviewer: Do you think you would be…fi this were in place, do you think you woudl still have kept your job?

Respondent: Yes, I think it would massively impact my sister’s and my life if he got into a care home, because of his care needs, it would take a lot of the responsibility off us and we wouldn’t have to check that he’s been given his medication, we wouldn’t have to pick it up, we wouldn’t have to, you know, chase up all of these different services, because it would sort of be integrated from that building.

Interviewer: Yeah, I mean, they would take charge, isn’t it, they would have that overall view and because your dad is there every day, they would know him and how to handle him.

Respondent: Yeah, and they would be able to feed that back to the healthcare providers instead of us being the point of contact for all this information.

Interviewer: Yeah, okay. Good. And would you say your anxiety levels would be lower, you know, if I put something in place that would help, I’m trying to understand what should I evaluate, you know, in terms of change. So let’s say if your dad gets access to the CHC and is put into a place where they are kind, they know that it’s HD, it’s not him being nasty, you mentioned that you think his mental health would improve, you could work and have a life…

Respondent: Yeah, definitely.

Interviewer: Do you think, for example, in terms of your anxiety, you know, your own health?

Respondent: It would definitely go down, yeah, I think I’d be able to have a bit more headspace, a bit more time as well to do more enjoyable things and not just work as a carer, yeah.

Interviewer: And both of you should have more quality of life?

Respondent: It would definitely make such a difference, like, even having a short break. Like, I left the town to stay with a friend for a few weeks, and it was a massive difference in my quality of life, like, not feeling like I’m on call 24/7, and I did feel my anxiety go down a bit, when I’m not in the area.

Interviewer: Yeah, okay. Alright, I’ve got a couple of boring questions now that I ask everyone. You already told me you’re [20-25] years old, [redacted]

Interviewer: Okay. Thank you. So [name 1], is there anything that we’ve missed discussing, something that you thought, “Oh, I really thought she was going to ask me this and she hasn’t”? Is there anything you want to add?

Respondent: I’ll just quickly scan the notes I made before.

Interviewer: Of course, yeah.

Respondent: I think we have covered a lot. Yeah, just it would be good if people were updated on their case status, so instead of having to call in to see and check where we are on the wait list, or if the case has been rejected or accepted, just have, like, automatic information sharing would be good.

Interviewer: With you as well?

Respondent: Yeah, because a lot of the times, appointments are made without confirming it with anyone because they know they can’t confirm it with my dad, they just don’t confirm it. And then they just show up at his house, which is also quite distressing for him, and they get inaccurate viewings, and yeah, it causes…

Interviewer: It’s a waste of time and it’s a risk to do that.

Respondent: Yeah, I mean, the GP, the one I sorted the other week, because he went in and my sister and I weren’t informed and he clearly didn’t take enough time with him, like, probably overwhelmed him a bit and…yeah, I wasn’t there in that situation, but I think it definitely could have been mitigated if we were informed beforehand.

Interviewer: Unless they like to be assaulted, why would you do that?

Respondent: I think they don’t really consider it an option, that family members would like to be informed beforehand, it’s just a bit, yeah, disrespectful to assume they don’t need to know. Disrespectful to my dad as well, just, you know, showing up out of the blue and giving no warning, he doesn’t have any privacy in his own home.

Interviewer: Yeah, well, again, what’s the win here, really, what was the aim? Because, yeah, well, that was a failure basically.

Respondent: Yeah, and we tried to update them, so, like, eventually they’ll get het message, or they won’t. But yeah, apart from that…no, I don’t think so. Is there anything that’s been unclear, do you want me to, like, clarify or put into different words?

Interviewer: No, I was just thinking about, you know, what you said now about having…you already had mentioned about data being centralised and different people with access, but really what you’re also saying is that you need some control basically over who is going and when, and some heads up, because you have your own lives, you can’t just…and you can’t guess, so one thing is to give you short notice, but another is to not give you notice at all.

Respondent: Yeah, it’s usually one of the two options.

Interviewer: Yeah, which isn’t great.

[00:59:01]

Respondent: Yeah.

Interviewer: And again, it’s a big risk, a hazard to have people coming in that speak only to your dad, that then get…either way, misread the situation and then end up being, like, discharged form services, when he shouldn’t be discharged, or unsafe for health professionals as well, which again, I don’t see how any of this, like, who would win on any of this. It’s a waste of time, like, so funding, so costly, and your father also doesn’t get a good assessment or his needs taken care of, so why? I was thinking…I was actually thinking, like, I’ve put my daughter into a holiday club for next week, for Easter, and I got automatically sent, like, an app with a password, so that I know what she’s having for lunch, what she’s doing on the day, and I’m thinking, you know, why… It has nothing, you know, like okay, I’m talking about a healthy child, but like, why can’t this, which is much more complex, so the need for co-ordination is so much higher, the need to know is so much more important, why can’t you know that? You know, why can’t you know if your dad ate his dinner, or if he had a bad night’s sleep?

Respondent: Yeah, that would be really useful for the carers going in, so they know, you know, if he’s been overwhelmed, if he’s had appointments that day, and physically can’t take any more information, can’t be, like, have small talk anymore, it would definitely help. We did have a similar kind of app with the first care company, they all seem to have different methods of recording what they do, but that one, you could only access it via a QR code which you had to be at his house to access the information, so that all kept it… But it was useful, but only if you were there, which obviously you need to know those things when you’re at work, or when you’re not there, it would be better.

Interviewer: Yeah, yeah, no, of course, I mean, you’re there, I mean, I guess it’s useful if the doctor, for example, has the time to scan the QR code before…

Respondent: Oh no, the doctor wouldn’t have access to it, so this was only for my sister and I.

Interviewer: Ah, okay, only for you guys, but you had to be in?

Respondent: Yeah, having a similar thing for everyone to access, like, every care provider, that would be really good, because then they’d all have the same picture of what’s happening.

Interviewer: Yeah, so this QR code also had his care plan, for example, or how he likes, you know, his likes and his dislikes?

Respondent: Briefly, like in bullet points. We’re not using this anymore because we’re on to a different care company.

Interviewer: Yeah, I understand.

Respondent: But yeah, a little bit, but it was always varied, the level of care, depending on who was going into his house and you know, just the day, because the symptoms vary a lot.

Interviewer: Okay, okay. I’m always surprised when, you know, speaking to people with lived experience of the…not just people with experience, but also, well, again, as you were saying, people that know Huntington’s Disease, and how it can affect someone’s life, and the ideas that they come up with to improve the system is, for me, it’s amazing.

Respondent: Yeah.

Interviewer: Okay.

Respondent: It must vary quite a lot from the different regions?

[01:03:17]

Interviewer: Well, I think unfortunately, where the problems lie are at this core, are actually the same. Because it’s not, what I’m seeing more and more, it’s not a Huntington’s Disease problem, it’s a system problem. So you know, if you tell me that, for example, you know, your father needs a more complex level of care, that you’ve been waiting since last June to get an assessment and you know, these are not eve particular just to Huntington’s, the fact is Huntington’s is extremely complex, and it really highlights the cracks in the system, because it bridges the physical health and the mental health, it bridges, you know, care from healthcare to social care, so it really brings out the worst in the system.

Respondent: Yeah, all the gaps.

Interviewer: That’s what I’m seeing basically, but it’s not… So unfortunately, I mean, of course, for example, you told me you don’t have access to Huntington’s Disease specialist nurse, your HDA advisor is covering a really wide geographical area, you know, like, so it does, that varies, the resources vary, but a lot of the complaints in terms of social care, mental health, are being quite evident across the country. But I’ve also had my, you know, better experiences, people that are happier, but still it does touch on many of what we spoke today. I guess when people say they’re happy, it’s because they’ve heard so much worse that they compare themselves to that.

Respondent: Yeah, definitely.

Interviewer: Next week I’m in the Netherlands, visiting facilities that are experts in Huntington’s Disease care, and I’m quite, yeah, I may get a glimpse of what excellent and real looks like, and bring ideas to England.

Respondent: Yeah, I think sometimes it’s hard to imagine what ideal care would be like when you sort of want the basic needs to be met, but…

Interviewer: Yeah, because we look at…there’s always worse, isn’t it, there’s always worse, and then we’re, like, “Well actually, no, it could be worse.” So we’re sort of, like, “Oh,” we have a sense of relief.

Respondent: Yeah.

Interviewer: Yeah, well, that’s…

Respondent: This is great.

[redacted]

[End of Transcript]