58m 21s

Interviewer: 0:18 Alright.  
Uh, so have I have a warm-up question just to start up: if you are OK with sharing a bit of your connection to Huntington's disease with me.

RESPONDENT: 0:31 Yeah.  
So, uh, see passed down through my family.  
My grand-dad had it, but I never met my grand-dad because he passed away before I died. Before I was born, umm, my dad had it and my auntie.  
They both passed away now.  
Uh, my brother and sister they have both been tested, but they are both negative, so they were both lucky, but unfortunately have been tested and I'm positive so… I was tested when I was 18, so seven years ago now.  
So I've known for a while.

Interviewer: 1:11 OK, wow.  
And you're….Yeah, I mean you, you tested then as straight as you turned 18 and you could do the test. You went for it.

RESPONDENT: 1:18 Yeah, yeah.  
As soon as I could I I started, yeah.  
The kind of meetings with the GP’s and stuff before I even turned 18 so I could get the ball rolling as quick as possible because I want it to find out.  
I think I just didn't like not knowing.  
I just wanted to know and have it have it, for certain, neither away and I could deal with it so.

Interviewer: 1:42 And your siblings are older or younger or middle?

RESPONDENT: 1:46 So yeah, they are both older. My brother is [4-6] years older, he is in his early 30s and my sister's [less than 5] years older than him, so she is [redacted].

Interviewer: 1:59 When they did, you already know they were negative when you decided to test?

RESPONDENT: 2:05 So my brother got tested a few months before I started my testing.  
Uh, where's my sister only got tested last year.

Interviewer: 2:13 OK.

RESPONDENT: 2:14 Only recently.

Interviewer: 2:16 OK, alright.  
Well, thank you for sharing that.  
Sorry about your dad, auntie and grand-dad, you said.

RESPONDENT: 2:23 So.

Interviewer: 2:24 OK, So what sort of care are you under now, if any. I have not looked at your survey answers alright, so I'm sorry if I'm for covering some of the questions.

RESPONDENT: 2:44 That's fine and so obviously I went for the testing and went for the genetic counselling, so that was kind of a period I was constantly speaking to people about Huntington's, and as soon as I had my result they offered me continued counselling.  
And so I could meet with them regularly if I wanted to, obviously haven't got symptoms at the moment, so that was that was just optional, weather I saw it as helpful or not. I moved up to Uni shortly after that, moved to [location 1].  
I decided that I didn't really need them at the moment.  
Uh much carry on with my life as usual, just I haven't had any meetings with them since, so I left that  
But then I've carried on with. I've tried to get involved with this many studies as I can.  
Uh, it's gotta be proactive in that sense.

Interviewer: 3:41 How do you find out about the studies?

RESPONDENT: 3:47 Uh, different ways, I got told …I had an email from them about the first HD??? study.  
With [HD clinical-academic expert] team, uh so found out about that one from my old genetic counsellor.

Interviewer: 4:03 Umm.

RESPONDENT: 4:05 Then they did the second round of that last year.  
And but [HD clinical-academic expert]’s team contacted me because obviously I was on the books from doing it the first time.  
So I found out about that one through that.  
And then sometimes I just look on what ongoing studies online and find them online or HD buzz.

Interviewer: 4:26 Umm.

RESPONDENT: 4:28 One of the other Huntington's kind of news outlets.

Interviewer: 4:32 Are you from [location 1] or you're just studying in [location 1]?

RESPONDENT: 4:36 So I'm from [location 2] in Southwest.

Interviewer: 4:37 You're from [location 2].  
OK, alright.  
OK.  
And you're in [location 1].  
Alright.  
Umm, OK yeah, it was just.  
Yeah.  
It's interesting to see how people get hold of the information.  
Of course, you're quite young and I'm sure you're super comfortable using like social media and you know, and that it's always popping up, isn't it?

RESPONDENT: 4:54 Yeah, I I.  
Yeah.  
And obviously the field I'm in. I am aware of studies, they're going on constantly, Cause I am constantly writing papers and stuff and.  
For example, your study showed up on one of the websites I was on.  
So that's how I found out about yours.  
And that was for a research I was doing for a paper so.

Interviewer: 5:23 Hmm, interesting.  
OK.

RESPONDENT: 5:26 Yeah.

Interviewer: 5:27 And your genetic counsellor. Was it in [location 2] or was it at [location 1]?

RESPONDENT: 5:37 That was back in [location 2], [location 5].

Interviewer: 5:39 That was back in the [location 2].  
OK, alright.  
OK, so in [location 1]… they left sort of like the open door for you, if you wanted to continue having counselling, but you were like, yeah, but I don't have any symptoms now and I'll move on with my life.

RESPONDENT: 5:49 Yeah.

Interviewer: 5:57 You went to Uni and I'm sure you have like, lots to do and think about every day and since then you haven't connected with other services, or are you in contact with other services?

RESPONDENT: 6:02 Yeah.  
So it's basically… I had two genetic counsellors back when I did the testing and then since then, uh, both of them have retired. So they gave me contact details just in case I ever needed to speak to another genetic counsellor back in [location 5]. I contacted them a couple of weeks ago for the first time, pretty much in 7 years, because I heard about the Tominersen recent drug trial, and they were restarting it with younger participants.

So I was contacting them to see whether I was eligible for that 'cause I knew they were looking for… It sounded like my age group from speaking to members of [HD clinical-academic expert]’s team. It sounded like I would have been eligible, but once I, once I actually went down that route and spoke to someone.

They put me in contact with someone from [location 1] Hospital, who told me that my CAP score was nowhere near where it needed to be for umm, that study.

Interviewer: 7:18 Too early?

RESPONDENT: 7:20 Yeah, way too early.

Interviewer: 7:21 Yeah.

RESPONDENT: 7:21 Yeah, it's really surprising really.

Interviewer: 7:24 It's a real… I'm sorry, it's probably extremely frustrating.  
It's a really narrow window.

RESPONDENT: 7:32 Yeah, it's.

Interviewer: 7:32 You need to be sick, but not too sick, quite early. It's hard…

RESPONDENT: 7:32 I think it's quite odd.  
It's quite….

Interviewer: 7:38 Hard to know when to jump in.

RESPONDENT: 7:38 Yet yeah, when I heard it, when I read the the kind of eligibility criteria saying, uh, kind of prodromal stages and.  
But but but the CAP score they were asking for is actually quite severe.  
It’s a lot more severe than what I was expecting because that's…. I was trying to put in context with what my dad's and I'm trying to… my dad's CAP score would have been when he was in his 40s, when he was in a care home, when it still wouldn't have been sufficient.  
Still would have been under the CAP score needed for the eligibility.

Interviewer: 8:09 No….

RESPONDENT: 8:13 Eligibility, but the the title of the paper was called early stages and prodormal.

Interviewer: 8:14 Hmm.  
Yeah.  
I mean, I haven't seen the protocol for Generation HD II, but from what I read and having led on Generation HD I, I would expect as you are saying that you would be a good fit.  
I also thought they wanted quite early stages. Umm.

RESPONDENT: 8:40 Yeah.  
Yeah.  
Where's the CAP doesn't really look like that.  
I think they changed the CAP score compared to generation HD-1.  
They're using different parameters or something, but yes, a lot later stage then I was expecting.

Interviewer: 9:01 I'm sorry for that, [RESPONDENT: name].

Interviewer: 9:03 Frustrating to say the least, and and so you contacted the research team at [location 1] Hospital and they said, well they, they, you you're are you enrolled on the Enroll study?.

RESPONDENT: 9:11 Yeah. So yeah, I tried to sign up last year.  
But they weren't taking any new participants because they were…

Interviewer: 9:25 The backlog is massive.

RESPONDENT: 9:29 Yeah. So I was told to to hold off and then I only found out because I get sent like.  
Because I'm part of the faculty of life sciences University of [location 1], they sent the [geographical area related to location 1] updates.  
That was reading the newsletter and then saw on there that it was open again. So.

Interviewer: 9:47 Hmm.

RESPONDENT: 9:53 Sent them… spoke to my genetics counsellor and said I need to get back on that and she got in contact with them and managed to get me. So I've got a meeting next week, so I'll be signed on from next week.

Interviewer: 10:04 OK.  
Alright, at [location 1].

Interviewer: 10:08 It's good to know that they're back on the horse.  
The backlog was massive. OK.

RESPONDENT: 10:11 Yeah.  
It's quite surprising… it’s such a rare disease that you...

Interviewer: 10:17 Umm well yeah, I'm sure they'll explain to you, but it's basically during COVID we couldn't do visits.

RESPONDENT: 10:25 Right.

Interviewer: 10:25 So the amount of visits we were owing to the patients we already had was big and then we got a big transfer from a different county where the team, well the consultant retired.  
So all the patients got transferred to us as well.  
Well, not to us, because I've left them.

RESPONDENT: 10:42 Uh.

Interviewer: 10:43 But yeah, so there was like just a build up and then we didn't have staff to work and and Enroll is quite a a specialized study in terms of the assessments we do.

RESPONDENT: 10:51 Yeah.

Interviewer: 10:56 And then I left, which I'm sure didn't help and I was doing a lot of the visits.

RESPONDENT: 10:56 Hmm.  
Yeah.

Interviewer: 11:01 So yeah, I.

RESPONDENT: 11:02 Yeah, I I I I don't think I appreciate it.  
When I heard about Enroll, I thought it was more of a register than like constant ongoing test.  
Like if, you register on, it was like have your details for the future.

Interviewer: 11:16 Yeah.

RESPONDENT: 11:16 I didn't.  
I didn't realize how intensive it is. Yeah.

Interviewer: 11:17 Yeah, for you.  
It's just once a year. But then you have.  
They'll do cognitive tests.  
They'll do behaviour tests and motor tests.

RESPONDENT: 11:27 Yeah, blood tests.

Interviewer: 11:29 Yeah, but it's it's these bits of the psychiatric assessment, cognitive and motor, that takes time to train a new nurse and that's the bits.

RESPONDENT: 11:36 Yeah.

Interviewer: 11:39 For you it will be fine, but it takes a lot longer to train a staff member than the visit is gonna take to do.

RESPONDENT: 11:45 Yeah.

Interviewer: 11:46 OK, I'm interested because you are at the university and my project looks at different sectors and I'm interested to know if you had the need to speak to any one at the university about hum… your gene positive test or if that hasn't happened or.

RESPONDENT: 12:12 Uh, I had a conversation with my tutor when it, like my second year, because that was the year my dad passed away.  
So I explained obviously what was going on.  
I had to go home for a bit.  
Uh, he wasn't very well.  
So I explained the situation with him and then he asked, because he’s a neuroscientists as well. He asked if I knew my result, if my results arrived, so, he knows.  
And then I told my supervisor recently because I'm going on so many different… like the Enroll and I've been away for the HD 2.0 as well.  
I go away for these these studies and stuff, but it's it's just useful to make sure she knows.  
So she can.  
She doesn't think I'm being lazy.  
I'm just.

Interviewer: 13:03 Yeah, yeah, yeah.

RESPONDENT: 13:03 There's a reason there's a reason I'm not there, so I don't.  
I don't usually tell many people, but yeah, I've told a couple of people at university.

Interviewer: 13:14 OK.  
And you feel that they've given you?  
I mean, how do you feel the support has been for you?  
Enough, not enough or.

RESPONDENT: 13:24 Yeah.  
Yeah, it's been good.  
It's that they kind of.  
Uh, the most, the most common response.  
It gets kind of like, Oh yeah, we won’t question it just like, well, you do what you need to do  
So there's there's kind of that's all I need most of the time.  
It's just.  
Uh.  
Freedom to kind of do what I need to do if I need to go away.  
If I need to go to [location 4] to take part in a study or.  
Have any appointments or … with my dad being ill go and visit him like just to be able to do that and not worry about what exams and stuff they've given me special consideration for exams before, so where I had to go back for my for my dad, I got an extension on a on a project and it's supposed to be due in that week and only had a week to do.  
But I wasn't there for the entire week.  
So they gave me the extension for that.  
So just stuff like that where it's would have been really difficult to do well otherwise.  
Just allow me to do what I need to do.  
It's all I needed.  
Support was really good.

Interviewer: 14:30 Yeah. OK, alright.  
That that's good to hear.  
And and with your.  
Like follow up care or?  
Do you?  
I don't want to lead, so are you happy with how things are in terms of?  
Umm.  
Leaving it up to you to reach out if you need help.  
Does that work for you like that or...

RESPONDENT: 15:05 Yeah.  
Yeah, I'm.  
I'm fine.  
I think I'm.  
I manage it I.  
I've got a good support network kind of worth in of like family members who obviously understand that obviously would it's it's a family condition that me, my brother, my sister, we've all dealt with, throughout our lives, so got good support from them.  
And support from my girlfriend and a friends and.  
I I kind of don't feel I need a huge amount more.  
Uh at the moment so.  
Yeah, I think the but for this stage of the disease where it's kind of haven't got the symptoms just dealing with the diagnosis it's I I don't think I need anymore.  
So I'm going exactly and the option, I'm aware there's the doors there, the the options always there, if I want to go speak to someone at [location 5] hospital, and the genetics councillors have been brilliant. So.

Interviewer: 16:02 Hmm.

RESPONDENT: 16:14 So I can't really fault it so far.

Interviewer: 16:18 Do you ever go to the GP instead?  
Or you connect with the counsellor.  
Would you connect with GP or mainly the counsellors?

RESPONDENT: 16:27 I did recently with the study.  
Just because I thought it was basically about in contact with the Roche Pharmaceuticals first year relevant to medicine study and then they said I need just a doctor to.  
Uh, refer me for the study. I couldn’t refer myself or just get in contact with them directly.  
I need to go to a doctor first, so it's the GP and then they didn't really know what to do.

Interviewer: 16:53  
Hmm.

RESPONDENT: 16:56  
So then they told me to go speak to the genetics counsellor and … I also had some weird, weird conversations with the GP’s.  
Clearly don't understand Huntington's all that well, but as it’s a rare condition I can't blame the huge amount, but.

Interviewer: 17:11  
Is your GP, the same that your dad had or?

RESPONDENT: 17:18  
Now I've gone through loads of GP’s.  
So the GP I went to last time was the first time I've been with him, and then in [location 1]  
Uh, But yeah, I've been to a different GP every time pretty much.

Interviewer: 17:36  
And then they, you're saying they don't seem to understand the disease.

RESPONDENT: 17:42  
Uh, sometimes, obviously.  
Uh, sometimes they they understand, very like, pretty well.  
But yeah, especially the last couple of GP's I've spoken to.  
Said some weird things about not really understanding how my brother didn't have Huntington's, but I did.  
Obviously not understanding the disease.

Interviewer: 18:11  
Yeah, that that pretty much tells it, isn't it?

RESPONDENT: 18:15  
Yeah, but yeah, part from that, it's been absolutely fine.  
But when it comes my care so far, it's kind of, the latter stages of the season I have issue with, kind of the care.  
I don't know whether that's skipping questions that you were probably about to ask me.

Interviewer: 18:35  
No, no, no, no, no.

RESPONDENT: 18:37  
It's.  
Yeah, but cause obviously when it comes to my dad's care though, had a lot of issues with my dad's care.  
But uh yeah.  
I thought with mine because I've not really got to that stage yet where I need that intensive intensive care.  
Yeah, I don't have those issues so far.

Interviewer: 18:57  
So are you you're worried with how it's gonna look like in the future when you get symptoms?

RESPONDENT: 19:07  
Yeah.  
Yeah.  
If it's anything like my my dad's.  
It wasn't, wasn't good at all. Umm.

Interviewer: 19:15  
Why wasn't it good?

RESPONDENT: 19:17  
Uh, so when, when my dad first start getting ill he was kind of looked after, he ended up moving with my Nan or his his mum.  
And was kind of getting looked after by her as he was getting worse and worse.  
And then she ended up passing away.  
So then my dad was in the same house, but then my auntie, got sick with Huntington’s as well.  
She was looking after him. And struggling and there wasn't much support there for her, trying to keep it looking after someone with Huntington's by herself, when she was barely capable of looking after herself anyway, so my brother he was properly 17/18, was trying to care for my dad as well and go over there and look after him.  
Uh and I, I would have been.  
11 or 12 at the time.  
And trying to manage that as well and then it got to a point where he couldn’t stay there anymore. He ended up getting called cause my dad was kicking off and, obviously anger is part of the disease.  
Anyway, but when he's not getting the care, sufficient care as well, it's more frustrating for him.

Interviewer: 20:36  
Of course.

RESPONDENT: 20:38  
So then he ended up getting moved to the care home.

Interviewer: 20:42  
In [location 2]?

RESPONDENT: 20:43  
In [location 2] yes, standard old people care home, he was by far youngest person there.  
Kind of, out of place, and they didn't didn't really know how to deal with them.

Interviewer: 20:58  
Do you have any recollection of? I mean, you were quite young and of how easy or how hard it was to find a nursing home for him?

RESPONDENT: 21:09  
Ah, it was always really, really difficult.  
I think that that first one he went to, he was kind of put in there very quickly and just kind of chucked in there, but he didn’t li stay there for very long, it's just the local one and they made it pretty clear that couldn't look after him.  
So then he ended up getting moved. Umm.

Interviewer: 21:36  
To who was arranging these? Uh.  
You still there?  
Hello.  
Oh, there you are.  
Sorry, I missed you for a minute.

RESPONDENT: 21:48  
Yeah.

Interviewer: 21:49  
Yeah, it's just froze.  
I was gonna ask who who was dealing, who was arranging for the nursing home, nursing homes?

RESPONDENT: 21:54  
So.  
Yeah.  
So it's quite a difficult part for my brother because he had to deal with most of it even though he was only 17/18, there really wasn't anyone else to do it.  
My sister, even though she was older, she was two years older than him, she would have been in her 20’s.  
She would have been at 20’s at the time, [year].  
I feel like she wasn't mature enough to kind of deal with it or didn't want to, and she kind of found it quite difficult to deal with my brothers.  
Probably my brother’s the most mature out of the two of them.  
So he ended up taking over and trying to make sure he got the care he needed and he was going to meetings with.… When they got some assessments done for different payments and…  
Is it PIP the the payment?

Interviewer: 22:52  
Yeah.  
Yeah.

RESPONDENT: 22:55  
Yeah.  
So he was going for meetings to try and get him the the money needed to pay for the care and do all of that.  
When he was only 17/18 and then trying to organise where he was gonna get moved to, because they were saying they weren't going to keep him there, and all the care homes were turning him down.  
Uh, because especially, my dad was fairly a big Guy, 6 foot two.  
and, quite heavy as well.  
So he was still in the stage where he was still mobile, still able to walk around, but also he's hallucinating and losing grasp on reality at the same time.  
So he was in difficult stage of the disease and.

Interviewer: 23:37  
Why?  
Why do you think he was being turned down by the nursing homes?

RESPONDENT: 23:42  
Uh.  
Because because of the size and the kind of they didn't have, they realized that they would have to have more staff to watch him.  
They would, they would have made back with the money they would have got.  
So it wasn't financially viable for them to take him.  
It's kind of my understanding of…Obviously I was young.  
I was 14/15, but that's kind of my understanding of it.

Interviewer: 24:04  
Yeah, of course.

RESPONDENT: 24:07  
It's he was they, especially when most of the care home staff they were meeting were women who were, uh, five foot Five Below, like trying to look after a 6 foot two heavy blokey.

Interviewer: 24:23  
Yeah.

RESPONDENT: 24:24  
Heavy bloke wants to walk around and kick his legs around and throws arms around there have to have four or five of them just to kind of do anything with him.  
So it wasn't very struggling financially to to make it work.  
I mean, there's no incentive for them.  
There weren't any extra money from or as I understood it.  
So he ended up getting moved to hu… [location ] Care home, which is first from from [redacted], is probably an hour and a half.  
Uh, it’s the other side of the county.

Interviewer: 25:00  
Umm.

RESPONDENT: 25:01  
Uh.  
And he stayed there for leave us a few months and then got moved to all the way to [location 3] on the other side of the country.  
And which was the only place that would take him, so so got moved all the way across the other side of the country and obviously me, my brother and my sister were all fairly young.  
We didn't have.  
I couldn’t go and visit him anymore because I was 15/16 and he was on the other side of the country.

Interviewer: 25:29  
hmm

RESPONDENT: 25:32  
Also wasn't allowed to go visit him because you had to be 18 to go into the this care home because it was a mental mental hospital as well.

Interviewer: 25:39  
Oh, OK alright.

RESPONDENT: 25:43  
So for visits I had to be.  
Uh, right to go with someone over 18, had to go with my brother.  
And then even when I turned up the first visit, they still tried to turn me away.  
Because even though we've spoken to on the phone and organized, and I said I'm I'm under 18 by need to see my dad and he lives there.  
So there's no other way of me seeing him.  
Umm that they organised the visit so that they can bring him outside and you can meet him outside.  
When I actually got there, they said  
Oh, no, you're not.  
You're not 18.  
You can't give go in. Even though we travelled all the way across.

Interviewer: 26:13  
Oh gosh.

RESPONDENT: 26:14  
They get there.  
So like that's though.

Interviewer: 26:16  
And that was you and your brother, traveling or anyone else with you.

RESPONDENT: 26:20  
Me, my brother, my sister.

Interviewer: 26:21  
You and your brother and your sister.

RESPONDENT: 26:23  
Luckily, my brother kicked off enough that they ended up changing their mind.  
Thank God for that, but.  
Yeah.  
Yeah, it wasn't.  
It was every step of the the kind of care was difficult.  
It was difficult to see him.  
It was difficult.  
Find him somewhere nearby.  
The care was never great.  
So yeah, it was.  
It was constantly frustrating, having to sort of the money.  
There's no one there to to try and support that kind of side of things.  
And my brother was the only person ended up getting into some horrible situations where they were asking for huge amounts of money in.  
That we didn't have and.  
Yeah, it was a lot… difficult.

Interviewer: 27:10  
Do you know?  
I mean, if there was a applications for PIP, usually there's a social worker involved, but you were so young you probably everyone was just like people coming and going and.

RESPONDENT: 27:24  
Yeah.  
Yeah.  
My uh, my brother mostly met all these people.  
At his place as he moved that, he'd moved out at this point.  
So, umm, no, I never really met the the social workers I went to any of those kind of meetings.  
But yeah, I just got told the results most of the time.  
I was probably at school or something but told afterwards.  
What?  
Umm, it's kind of the result.  
The meeting was, that was constantly happening, having different assessments and stuff.

Interviewer: 28:04  
So.  
Where was your auntie?  
If I may ask, because you said she.

RESPONDENT: 28:09  
So she she so she was living with my nan as well her mum.  
The the three of them were living together.  
When my dad moved out.  
So it's my dad, my auntie and their mom all living together.

Interviewer: 28:23  
Hmm.

RESPONDENT: 28:24  
Uh.  
My nan's house.

Interviewer: 28:27  
OK.

RESPONDENT: 28:29  
Looking after both of them.

Interviewer: 28:33  
And your auntie still with your non or.

RESPONDENT: 28:38  
No, my my mom passed away before my dad went into the care home.  
And then my aunties passed away a couple of years after my dad.

Interviewer: 28:46  
Oh, your auntie passed away as well, OK?

RESPONDENT: 28:48  
She she ends up going into the same care home because.

Interviewer: 28:50  
Yeah, that was my.  
That was my question here where?  
What?

RESPONDENT: 28:54  
Yeah, she she had a really steep decline.

Interviewer: 28:55  
What happened?

RESPONDENT: 28:57  
Whereas my dad took kind of 15/20 years to kind of the disease to progress.  
My auntie got diagnosed.  
Uh.  
She went into care home very quickly and then it was 2-3 years and she's she passed away.  
Uh, she had a really steep, really fast decline.

Interviewer: 29:19  
OK, so you don't need Care now, but you've seen your father and your auntie.

RESPONDENT: 29:30  
Yeah.

Interviewer: 29:31  
Going through what seems quite difficult, difficult situation and you were particularly young, so you were telling me that you well, that's that's what I got from what you were saying, that you're to, like, not worried now, but you're worried about the future.

RESPONDENT: 29:40  
Hmm.  
Yeah.  
Yeah, for sure.  
If it's anything like that, then yeah, I'm worried about how far I'm gonna get moved and how far kind of people would want to visit me and what kind of family is gonna have to travel to to kind of see me if I if I got to that stage and.  
Yeah, but just the way it was all handled.  
And.

Interviewer: 30:16  
Which is completely understandable.  
Uh, so one of the?  
I asked you earlier about umm, why do you think the nursing homes were refusing to take on your dad?  
And because quite often, nursing homes UM do not want to accept people with Huntington's disease because they're too complex or too young to fit in the elderly care home.

RESPONDENT: 30:28  
Yeah.  
But I think a lot of it as well because I had this conversation with my my girlfriend is a nurse.  
She used to work at [location 1] Hospital.  
She she's moved.  
[location 4]  
She she deals with a lot more Huntington patients now and.  
A lot of them get a bad rap because the obviously the disease, a lot of the the first symptoms are kind of mood changes and anger and there's a lot of kind of difficult personality traits that get a lot worse before as the disease gets stuck.  
Kind of.  
Early stage.  
And that's not showing up. To the people who are caring for those who don't know them very well and don't know understand that that's not what they're actually like, that they were different person before the disease got worse. They kind of think, “oh they are a horrible person. I don't want to deal with them.”  
Uh George. who’s the Huntington’s down the way he's he's a horrible person. He keeps shouting abuse at us like they they kind of get that kind of rep and then the the carers don't wanna give them as much kind of time and effort. Uh.  
So so I think that's that's part of it is that that they're not easy people Uh patients to deal with.  
As the disease progresses and I get that.  
But it's it's part of the disease.  
I think there's some kind of see through that and see that, that, this, this is part of the disease. It's not.  
It's not like part Parkinson's, where it's primarily motor, there's the two elements to Huntington’s, the psychological and the the physical.

Interviewer: 32:44  
You're very wise.  
OK so.

RESPONDENT: 32:48  
Thank you.

Interviewer: 32:52  
So what do you?  
What do you think?  
Would be more like more important regarding care or support for you right now.  
What would make you feel more comfortable about the future?

RESPONDENT: 33:17  
I think knowing there was support, to the people, the the family members who have to kind of deal with organising all of this who don't did this the first time they've gone through it most of the time like.  
There needs to be support around how their care is managed, how they understand what's gonna what's gonna happen and. And how it's all going to be handled in terms of financial assistance?  
Uh.  
Which can happens.  
They'll probably end up at going to uh… on that side of it, then also to know that there's a…There’s a good number of care homes or hospitals in in proximity which would take me if I got so the last stages I wouldn't have to travel far.  
So family wouldn't have to travel far.  
I think the the main two things support for the family and they would have to travel far and then actually good quality care.  
That I I think.  
Especially it goes into it when they get moved into private care homes.  
Uh.  
Which kind of aren't overseen by the NHS.  
The they kind of other different standard of care.  
As far as I could tell.  
So I was young when my dad was going through this private ones.  
It was odd. Odd situation going . Cause my dad…a private care home where… I don’t know…they just had ways of doing stuff.  
And it was.  
It's very odd

Interviewer: 35:24  
Odd better or odd worse, what's your perception on private care?

RESPONDENT: 35:32  
Uh.  
Yeah, I think odd worse. It's like the social focused on money and it running it as a business that you still like the care kind of gets pushed to the side sometimes.   
They’ll only have the minimum number of stuff they need … everything's minimum and. In the care homes he went to.  
And just some some circumstances where you wanna what walked into especially the first guy that we took him, it just felt.  
At the the owner was always walking around me, always treated it as if it was his home.  
Like and you were.  
You were coming in.  
It's like his house and you have to do what he said.  
And it was like it was very weird.  
Uh.

Interviewer: 36:23  
Christ.

RESPONDENT: 36:24  
Yeah.  
And it was just odd. It’s were my dad had to go at the time.   
Because no where else would take him at the time.  
So we don't have much choice, it was just.  
Yeah, that's weird situations that weird, but the the care staff there was good.  
They looked after him but.  
Again, because of the financial incentive, they wanted to get rid of him, the owner wanted to get rid of him, because they they knew they needed three people on them.

Interviewer: 36:56  
Hmm.

RESPONDENT: 36:56  
Worse, they couldn't afford to constantly have three people on it.  
So they wanted to ship him out as soon as they could, really.

Interviewer: 37:04  
Hmm.  
OK, so family support.  
And uh, basically appropriate long term care.

RESPONDENT: 37:14  
Yeah.

Interviewer: 37:18  
So facilities that can take people with huntingtons and take care of them properly.

RESPONDENT: 37:20  
Yeah.  
Yeah.

Interviewer: 37:26  
Sounds good to me.

RESPONDENT: 37:26  
And I think it's what's the facility like, obviously, like…  
The (?) kind of went through this built built like one facility in the in the UK, which kind of has all of them. But then your thinking. safety, built that facility in [location 4], everyone in the north of England then has to travel down. There’s a lot of travelling to do, you've got to have that level of care closer to, so that kind, of those areas.  
So you don’t have got to travel as far.

Interviewer: 38:00  
And when you mention family support, [RESPONDENT: name] in terms of like what to expect and.  
And help families prepare.

RESPONDENT: 38:11  
Yeah.

Interviewer: 38:11  
How do you see that looking?

RESPONDENT: 38:20  
Uh.  
I think like the the genetics counselors, the the same kind of ideas what they do now looking after, looking after the patient, but there needs to be a similar kind of thing, more, continuation of that for the families where they can go, they can go speak to their mind and someone checking in as well, saying:  
“How's everything going? Ohh, you've got this meeting about their care.  
Do you know this is available? This payment is available” and kind of signposted them to stuff they just won't be aware of because like for my brother trying to deal with it had no idea.  
He didn't know what the PIP payments were. He was just out of secondary school. He didn’t know what PIP payments were. He didn’t know how to fund his care home. My dad had no money to his name, so kind of, he couldn’t just magically pull money out to pay for the care.  
Uh, so yeah, just having more support there.  
I know my brother did have meetings from charities, he wanted to get in contact with them.  
I hadn’t met any of them. Uh, that was just him.  
And he wasn't lively happy with them.   
I don't know why, you would have to ask him.  
I think that the person who he spoke to, from the… I forgot the name of the main Huntington's charity, they got.

Interviewer: 40:10  
Huntington's association? Yeah.

RESPONDENT: 40:13  
Yeah, they got in contact with him.  
But when the guy spoke to was, I don't know, he just said he didn't seem to really understand the disease and uh and didn't really understand what my brother's going through and sounded quite complacent.  
Uh, so upset.  
I don't know.  
I've never met him, but my brother ended up not contacting them again.  
Didn't speak to them because he just didn't like how that was handled.  
For whatever reason.

Interviewer: 40:45  
Yeah, I mean that.  
Yeah, as you're saying, I I won't know until I speak to him, but that, that's that's your perception.  
That it put him off, something put him off.

RESPONDENT: 40:57  
Yeah.  
Something something put him off.  
So I I don't know what, I wasn't there, but he wasn't happy.  
And then we never had any more contact from them.

Interviewer: 41:15  
OK.  
Is there anything you want to add?  
From what we spoke so far, [RESPONDENT: name].

RESPONDENT: 41:23  
No, no.

Interviewer: 41:25  
OK.  
Umm can you can you tell me your age please?

[redacted]

Interviewer: 42:31  
All right.  
Um, the interview, I am assuming… you may have done this before, so you might be bit tired after this, cause I I'm poking probably around a few wounds.

RESPONDENT: 42:54  
No, that’s fine.

Interviewer: 42:55  
Umm so.  
Does anything else come to your mind to talk about in terms of what would make care better for people living with Huntington's disease?  
Aside from what we spoke.

RESPONDENT: 43:10  
Uh.  
Uh, I didn't mention that the care home he went to and [location 3] as well, that was.  
That was on Panorama at the time as well, but there was a lot of dodgy stuff going on there.  
So yeah, he ended up getting moved from there, luckily.

Interviewer: 43:36  
Did you just said that was on Panorama?!

RESPONDENT: 43:39  
Yeah.  
Yeah, it was.  
They did a documentary on that care home.  
There's was a lot of stuff going on there.  
Umm, the yeah.  
Dodgy stuff.  
So he end up being moved from there, yeah.

Interviewer: 43:54  
And he was moved from there.  
OK.  
But, I mean, do you know if it was closed or or?

RESPONDENT: 44:02  
I think I think it's still open for as far as I am aware, I think it was.  
Yeah, there were cases of like abusing.  
Oh well, this this happens twice in my dad's care there, there's this. This.  
Example.  
So we heard that there was on Panorama.  
I never watched the documentary, because I didn't want to at the time, but I know there was a lot of dodgy stuff going there. The care home itself, contacted us to say, no it was the care home, it was the hospital contacted us to say.  
Ohh where on panorama like and they were trying to cover their own backs basically, they sent us an email about that and then.  
Yeah.  
I just heard it was really bad and I didn't want to know anymore.  
I just wanted him out there.  
You got moved and he got moved to [location 6] and then one of the members of staff from there got fired for hitting my dad, got caught hitting him.   
You know, it's like.  
Almost forgot about. I feel I must have blocked out because that was pretty horrendous.  
Yeah, they they ended up getting taking that frustration out on, hitting him.  
So again, I don't really want to know much more about that God, then they were fighting.  
Umm, I went to see him as soon as possible after that, but yeah.  
Yeah, it's just like that.  
Different level of care and.  
Umm.

Interviewer: 45:43  
Yeah, I guess.  
Uh, it's more closed doors than an NHS hospital would be.

RESPONDENT: 45:49  
Yeah, I feel like, NHS is constantly overseen and that for diligence to make sure standards are met, yeah.

Interviewer: 45:56  
Met.

RESPONDENT: 46:00  
Yes, good.  
Two massive kind of failings in in his care home.  
Well, probably a lot more than that, but not remembering but.

Interviewer: 46:09  
I mean, I know the CQC is supposed to oversee… private institutions as well and and of course there's good and bad like there are, you know, incidents happen at hospitals as well.

RESPONDENT: 46:19  
Umm.

Interviewer: 46:27  
But.

RESPONDENT: 46:27  
I think I think it was the the, the owner and the the person kind of, but I think it's the owner or one of the managers at [location 6] who contacted us to let us know what happened.  
Uh.  
I contacted my brother.  
Obviously they were horrified by what happened as well, and you could tell and.  
But I think they were calling us because they wanted our permission to press charges.

Interviewer: 46:58  
Yeah.  
I was gonna ask if there had been any reimburse, I mean reimbursement because.  
No.

RESPONDENT: 47:06  
As far as I know.

Interviewer: 47:09  
OK.  
So I guess.  
More.  
Well, auditing or monitoring or just higher higher standards of care would be more reassuring.

RESPONDENT: 47:28  
Yeah.

Interviewer: 47:29  
No, I mean.

RESPONDENT: 47:29  
Alright, I think that comes with more numbers as well, staffing if you have more funding than it's more numbers.  
There's more people there.  
They don't feel like the staff won't get as frustrated there.  
There'll be people that other members of staff there safely, it will be less likely to happen, so they're always be 2/2 members of staff or someone closer by, umm, summarizing me kind of reduces the risk of these kind of.  
this kind of abuse.  
Yeah, I'm not sure what else really up from just keeping them little NHS and all controlled by the NHS but.

Interviewer: 48:11  
Can I ask the the nursing home where, UM, your brother had to push for you both to visit because you were still young, could.

RESPONDENT: 48:12  
Yeah.  
Yeah, this was the [location 3] Hospital.

Interviewer: 48:26  
Were you able to go back?

RESPONDENT: 48:28  
Yeah.  
When there a couple of times.

Interviewer: 48:29  
More often? Umm.

RESPONDENT: 48:31  
Yeah.  
And I think because I turned 18 while he was there.  
Uh.

Interviewer: 48:36  
Ah.

RESPONDENT: 48:37  
So I think most of the time I went back where I was after I turned 18, so I was able to go up and visit.  
Then I got start driving the car.  
So I drove up there with my but my my accent come.  
I went up on myself.  
And visit, yeah.

Interviewer: 48:56  
Umm.  
OK, so at least there weren't.  
Yeah.  
Well, you got lucky that you turned 18 then and they didn't put anymore fights about that, OK?

RESPONDENT: 49:08  
Yeah, but it's just, it's a difficulty of actually getting to see him at that age.  
Like I couldn't drive.  
I didn't have the finances to pay for fuel and travel up every free weekend or whatever had to be once in a while.

Interviewer: 49:22  
Hmm.

RESPONDENT: 49:24  
Yeah, it's made it very difficult while I was in sixth form, trying to do all of my work as well.  
It's it to make to have the time, my money, and yeah, let's do that journey because it's a long journey through.  
And (?) to [location 3], it's like 5 hours there.  
5-6 hours.  
There 5-6 hours back so long drive.

Interviewer: 49:47  
Wow.  
Gee, you can literally do Portugal north to South in that time, you know.

RESPONDENT: 49:52  
Yes.  
Yeah.

Interviewer: 49:55  
Umm [RESPONDENT: name].  
I didn't.  
I didn't ask you about your mother.  
Umm I I'm not sure if there's anything you wanna say about your mother.

RESPONDENT: 50:01  
Yeah.  
That they they divorced when I I was like [less than 5 years old].  
My mom and my dad.  
Kind of.  
Kept on Good, good term.  
So I went stayed with my dad.  
On the weekends, well it was my nan’s house, but I don't go visit my dad on the weekends and as I was growing up.  
She used to kind of try and try and take us his care home and that kind of stuff and trying to help around that kind of stuff, when we were young, but once we start reaching kind of late teens and my brother was old enough to drive for, we normally did those kind of visits.  
Yeah.  
In my brother’s car or sister’s car.  
She kind of cut contact with my dad.

Interviewer: 50:51  
Hmm.  
OK.  
All right. OK.  
Thank you now.  
OK.  
Thank you for sharing this bit about your life, because your life is also more than this.  
But these… good part and and UM, anything else that comes to your mind to discuss now.

RESPONDENT: 51:13  
Yeah.  
That no. So.

Interviewer: 51:23  
OK, I want to ask you because you were the first person I interviewed for the study.  
If you have any tips for me so that at, you know the next ones are better and and of course you know, you can be honest.  
I can take it.

RESPONDENT: 51:45  
No, no, I think this is pretty smooth for I think sending out the questions and kind of how you're gonna organize it was quite helpful.  
So you can, especially people who it might've been even longer ago, they they dealt with it or.  
Ohh yeah, people are my kind of situation where my dad, my dad's care was when I was younger and it's quite a while ago.  
Gives her a chance to kind of umm.  
Remember what What's happening to him before.  
So he would come into the interview and I I can kinda tell you everything I wanted to sell you.  
And they I don't know whether it's helpful for you to speak to my brother.  
I don't know what you wanted to do that I'm sure you'd be happy to, but get some more information from him.  
Who's actually hands on with with my dad's, my dad's care and find out what areas he found frustrating as he was definitely very annoyed.

Interviewer: 52:41  
Thank you for the offer for for now.  
I can only speak to people who are living in [specific counties in England] which is a bit frustrating.

[redacted]

[End of Transcript]