[Part 1]

[redacted]

Interviewer: So, these two parts are optional. So, the first one asks if you would want me to keep your details, so that if there is further research that you can participate, I would invite you and let you know about that further research, and you have no obligation of taking part. It is more like an FYI.

Respondent: I mean, I want to do the research, but at a point in my life, I have got a daughter, she is [18-20] years old now. She is having a great life. She doesn’t know what is going on, and I had that great life as well, because obviously when I was born, we didn’t know this was a hereditary disease through genetics and stuff like that. The technology wasn’t there probably. So, I am trying to avoid any, “Dad, shall we go here today?” or, “Can we go here?” “No, I have got to go to the hospital”. “What’s that about dad?” And it kind of gets to me, because I think to myself, you know I should really somehow be telling her, but I can’t because it is big news. It is huge news. So, I would like to, and I am going to say yes to this.

Interviewer: If at any point you change your mind, I can just update it without any issues

Respondent: That’s fine. I am going to say yes, but you might not get me responding to anything.

Interviewer: That’s fine.

Respondent: Until it comes to a point where my daughter does know, and then you are free to do what you like with me. It doesn’t really bother me. It’s just I don’t want to be doing something. I’d love to go onto a trial, but that trial would have an affect on me, or it may not work, or it might cause other problems, and then my daughter, “What’s wrong dad? What’s happened?” And it is those circumstances that make me think, “I have got to be there for her until the right time, and then she’ll understand it”.

Interviewer: Yes, you need to be available to the people that are important to you. That comes first.

Respondent: Yeah.

[0:14:12]

Interviewer: Okay. The second part is about if you would like to receive a summary of what I find on the study?

Respondent: Yes, it would be good to see that at the end of the day.

Interviewer: Alright.

Respondent: You’re obviously doing the pilot, and then trying to move this worldwide.…?

Interviewer: Yes. So, I’m trying to design what the intervention would look like based on what people tell me they need, and then I want to test it. I went to move it to a testing stage.

Respondent: Okay.

Interviewer: Okay, so can I just confirm you are living in [Location 2].

Respondent: I am living in [Location 2], yeah, [Location 3].

Interviewer: Okay.

Respondent: Or don’t you need to know that?

Interviewer: It’s alright. That’s the type of thing that will be cut off in the transcript so that people can't find you. Alright [Name 2], so I want you to tell me a bit about your experience with Huntington’s Disease. What stage you are at.

Respondent: I don’t see anything. I am constantly talking to my wife, “Did we do this yesterday? Did this happen yesterday?” Or you know, I might say, “Am I right in saying….?” “Love, there’s nothing wrong with you. These things did happen. We did go to so and so’s house. We did go to this party a couple of weeks ago.” You know, I kind of get this perception in my head that at some point either I am going to start shaking, or I am going to have some mental issues. I don’t know when they are going to happen. Nobody knows when they are going to happen, and if they did then they’d say, “Right, it’s going to happen at this point. We are going have to try and treat it etc”. So, that is one of the things that is bugging me about the disease. Am I going crazy? Am I thinking things that some members of my family are thinking, and they are not true, but even now they are still thinking it’s true? I saw a lot from my father. He said a lot of things that we thought were true, but they weren’t true So, its like, “Ah, that would explain the Huntington’s”. He’d say, “We won’t be talking to them again. We won’t be going around to their house anymore if that is what they are thinking of us”. And it was only afterwards that I think other members of the family said, “Yeah, your dad wasn’t well. None of that happened”. My wife was not sleeping around with everybody in the town. My wife wasn’t doing this”. Things like that. I mean, these comments, they were like heartbreaking. It was like, “God, I didn’t think she was that sort of woman”. You know, so it was only after a time, you know when we got older and my dad passed away, we kind of met these people again and they said, “Yeah, he was just accusing us of things. He did it to uncle so and so, he did it to auntie so and so”. I don’t know why he did it, but you’d probably say, “Yeah, that’s the symptoms of Huntington’s Disease, you think things are going on that aren’t really going on”. So, it was a tough upbringing, but we’re all together. Now we talk to all the family, and everything is back to normal. But obviously that is my concern, because it is happening to my brother as well. So, day to day I am always questioning whether something is going on. I never did it before obviously, but now it is like I want you to know as soon as possible rather than later where I have gone down a path where I am not willing to get any help from anyone, “I don’t need anyone’s help. I am alright”. It’s not where I want to be. I want to be there as soon as possible when it happens, or something starts to happen, that you guys can intervene and say, “Right, here’s how we can help. Here’s how we can take care of this with what medicine and what treatment we have”. I don’t want to be in a position where I am like my brother. I said, “I think you have got it brother, but you are not getting tested, so you are missing out on a lot of other things, because the government won’t help you here, the government won’t help you there, because as far as they are concerned it could be something else”. So, it is hard to get that through to him now, and he refuses to get tested.

[0:18:36]

Interviewer: And does he think that he is affected, but he just hasn’t done the test?

Respondent: He won’t do the test. He is too frightened. I mean, when you are not in the right frame of mind, it is a tough test to do. I mean, to me it was a no-brainer. I’ve have had 50 years of enjoyment, I’ve got a lovely child, I’ve got a lovely wife. I mean, why shouldn’t I get tested, and if I’m negative then my daughter is alright. I can tell her everything, and then tell her, “Look, you’re okay, you are never going to have it, unless your mother has something like it but hasn’t shown any symptoms”. Because she hasn’t got tested. She has no need to get tested. But yeah, that is where I am standing in my head at the moment. That’s the right time.

Interviewer: And you have been tested then?

Respondent: Yeah, I have been tested. I’m a [CAG repeats redacted] … you see, this is it, we don’t know what my parents … maybe my father was in the 40s, hence my brother and my sister have got it bad, yeah. And my mother might have had a 39, or 38, or a 40 and it has dropped down to me to a [CAG redacted]. So, I know it is not always the same, it can drop, and it can go up.

Interviewer: Yeah, it can vary depending on the previous. But also, that is not still quite straightforward how your parents … I mean, your father was affected but your mother wasn’t. Is that right?

Respondent: We have no idea. She died at [55-60]. She could have got to 70 and started to have the shakes and say, “Mum, I think if both mother and father have got it. Yours is like in the 39/38 region, and dads was in the 42/43”. I have neve been able to get the result from my brother…

[Connection lost].

Interviewer: Hello. Can you hear me [Name 2]?

[Part 2]

[0:00:00]

Respondent: Hello.

Interviewer: Hi.

Respondent: Sorry, my internet went.

Interviewer: I wasn’t sure if it was yours or mine because this transition happened today, and I don’t think my Teams is working 100%.

Respondent: I think I lost all my connections on my applications as well, so it was probably me. Can you see me?

Interviewer: No, but I can hear you fine. Oh, there you are. Yeah, you’re there. So, you were saying you are not sure if your mother was affected or not.

Respondent: We wouldn’t know, would we? If my mother was 39 and 20, and my father was (inaudible 00:01:04) I might have got the [CAG] from my mother. We have no idea of knowing unless we do a DNA test of both parents, because I find it hard to understand how it has happened to my sister quicker than me. For some reason we have always felt that my sister and that particular brother, there was always something different about them. I mean, we thought, “They are going to get nowhere in life. They just can't keep a job, they can do this, they can't do that”. It happened so early on in life. You know, I have always had a job, I’ve always worked. You know, the other ones are really educated. It is like, why them? I have no idea. Yeah, so I’ve no idea why. It could all become clear one day when everybody gets tested and we see the variations and everything, and we think, “Those readings, yeah we can see there is a variation here, and that’s a big change from 39 to 46. That is quite big, so it looks like your mother, her family might have had it”. So, I have never really got close to my mother’s family. They may have it in their family as well, but no-one really talks about it in the Asian community. It is like keep it quiet and don’t go around telling people, because you have got to get your children married. It’s a terrible thing, isn’t it?

[0:02:47]

Interviewer: This is exactly the conversation I remember us having some years back. I think that is why I remember you so well, because you were the first non-white, I think I told you, you were the only non-white British participant we had, and I remember discussing the implications on getting your children married and the secrecy.

Respondent: Yeah, it’s terrible.

Interviewer: So, you were saying your brother particularly doesn’t see anything wrong and doesn’t want to accept help.

Respondent: Well, I went to see him the other day. Now, he went through the same thing my father went through, he accused his lovely wife, they have two children, and one is darker than the other, and my brother is quite light like me. So, he has automatically assumed that because it doesn’t look like his colour skin, it looks like the wife’s colour skin. I mean, this is genetics, this is what happens. You know, he then accepted that, “This is not my child. You’re not my child. Your mother was sleeping around. she’s sleeping around now”. So, apparently she was sleeping around. He was giving accusations to a woman who I know, it’s impossible. And he makes stupid comments like, “Did you come all the way from [Location 4], did a four and half hour journey, then slept with my wife, and then got back into bed and your wife didn’t realise?” I’m thinking, “How could I possibly do that?” At the time I was confused because we didn’t known HD was in the family. About a month later my nephew rang me up, his mother had got HD, and he said, “My mother has got HD, you might want to get yourself checked out”. Then I started to read up on it, found out what it was all about, and I thought, “Could this explain my dad’s, all the accusations he was making, and my brother talking like this?” And he said, “Yeah, I think it is.”

Interviewer: It just clicked.

Respondent: It’s all related. So, right now he’s thinking, “I’m not compatible with her. I don’t trust her. I’m thinking of moving out. I’ll buy my own house”. He hasn’t got the money to buy his own house, but he has got this thing in his head that if he leaves her, he’ll buy a nice four bedroomed house. I’m thinking, “The house you live in is barely worth £150,000. How is £75,000 going to get you a four bedroomed house?”

Interviewer: It’s not rational. It’s not a rational conversation.

Respondent: And even when I said, “Look, there’s no way you can do that”. “I can do anything. What are you saying, I can't buy my own house?” “No, you can't buy your own house, but it’s not going to be a lovely house. You know, it is going to be a flat. You are going to have to use all your savings, and no-one is going to help because you don’t want to acknowledge that you have got Huntington’s”. Or he may have Huntington’s. I don’t want to get him angry. It’s hard to talk to someone when they are not reasoning with you. I just saw him this weekend, and that is what he was saying. I said, “You can't do that. You know, there’s no way in a million years that you will be able to survive alone”. “Oh, I can make friends”. I said, “We can all make friends. It is not difficult to talk to someone. But friends are people that are really close, and it is difficult to make that close connection with someone when you have all got these, ‘I can't go out today, I don’t feel like going out, I am going to stay in’”. Friends want you to go out with them and have a meal, and go here, and go there, and meet up at the cinema, and have a good chat about things.

[0:06:41]

Interviewer: Yeah, it’s not about helping you buy a house.

Respondent: Yeah, it’s tough. So, I’ve had a tough weekend.

Interviewer: I’m really sorry. You know, I can see you are in a very difficult position. In this situation where you see your loved one needing help, but they don’t want help, what would help in this situation? What do you think would help?

Respondent: There is nothing you can do. Apparently, he has got to consent to everything, hasn’t he? Unless he does something really outrageous, and the government puts an order against him saying he must get tested. There is nothing we can do, is there? There is nothing you can do to make him get tested, force him to get tested. It is like a death sentence as far as they are concerned. Now, I knew it was a death sentence if I was positive, but I don’t think it is now. I think it’s the people around me that are making me feel like it’s a death sentence, because they are my family, aren’t they? It’s tough for me now. So, I’ve inherited the disease, but I’ve also inherited all the problems associated with the disease.

Interviewer: Yeah, because it is bigger than you, and it weighs more because of that.

Respondent: I mean, if I didn’t have any family connections, if it was just me dealing with it, I would probably be okay and get through it until a certain age. I don’t know.

Interviewer: And your daughter, is she an adult?

Respondent: Yeah. Well, she’s [18-20]. She’s doing her degree, so I don’t want to say, “Here, I’ve got some news for you. What’s the point of studying? What’s the point in this? What’s the point in that?” Life is short, I might as well go and enjoy it. Let me go on holiday, let me experience life before this kicks in, if I have got it. Because I think there is a terrible thing that if you do have it, there are certain things you can't do, you know. You can't get a £500,000 mortgage out. The banks will say, “Oh, there is the potential that when you get to 40 you are gong to have Huntington’s and be unable to pay this”. There is nothing to help people that have got hereditary diseases to get money to do things. It makes life complicated, and rather than just say, “The government will support those people in buying that £500,000 house because they have got a nice job and they can afford it now, but obviously come 44/45 when they might get Huntington’s, we will protect them against it”. It kind of limits your scope. So, the children that do know, from like my elder brothers and everything, they all know, because they are all older and working, done their degrees, and they need to know now, but they are obviously looking to get married or find someone. So, we told them. We said to them, “You can't test yourself, because if you want to make a big venture that is going to cost a lot of money, banks might not give it you because they want to know, ‘You never told us you had Huntington’s Disease and you got tested positive’”. So, it’s a bit of a … not only does it destroy you because you know you’re going to get it at one point in your life potentially, you are also restricted on what you can do for the future. I mean, the great thing is travel insurance, I don’t have to mention it to them because I am not symptomatic. So, that is a great thing, but I have to tell the bank that I have got it if I want a loan for 30 years.

Interviewer: Is that right?

Respondent: I think so, yeah.

Interviewer: I mean, I am asking because I know the Huntington’s Disease Association has done a seminar on insurance. I don’t think I could make it, but I got the idea that if you are at risk or positive but asymptomatic, you don’t have to disclose it to insurers, but don’t quote me on it. But I can see that basically that just adds to your concerns in terms of the future.

[0:11:17]

Respondent: It’s a financial hindrance to be tested, I think. But there’s nothing you can do about it. It makes sense, doesn’t it? I mean, you don’t want to be giving somebody a huge loan when you know potentially at 44/45 they can't pay it off, and the next minute the bank is having to sort it all out rather than myself, because I will be in a state. I don’t know. I don’t even know if I am supposed to tell them. Well, I am supposed to tell them when I’m symptomatic. So yeah, I don’t know. But you could investigate that for me and say, “No, the law has changed now, regardless of whether you have got it or not”.

Interviewer: Yeah, I will have a look, because I would like to know. I will add it to my to-do list.

Respondent: I mean, I don’t know where you are going to get that information from. Probably the banks are the ones that assess people’s credit risk. That’s what it is, isn’t it? It’s credit risk.

Interviewer: So, [Name 2] if you don’t mind me going back to health. So, you say you are asymptomatic, but sometimes there is things that happen, and you worry if it is the disease starting.

Respondent: Yes.

Interviewer: Who do you speak to then when you have these concerns?

Respondent: My wife. I trust her 100%. I keep saying it to myself every day, “I trust you 100%. Anything you say to me, I must believe”. I have to trust someone, don’t I? Someone has to tell me when something is happening to me that is not right. I dropped a cup the other day, but I knew why I dropped it, and she knew why because she saw me. She said, “You hit the corner of the table, and obviously you let go of it and it smashed”. So, it is a normal accident. It’s not because you are starting to shake or starting to lose focus. So, I haven’t done anything stupid like say constantly walking into doors, you are slipping on the floor, or you are wobbling as you are walking. You know, there is no signs of that. I am walking properly, I am on the treadmill, I am running. I am just worried at when does it start? If it ever starts.

Interviewer: Who would you speak to then, if these concerns start to be more frequent and you think, “I should really speak to someone”.

Respondent: Well, the girls at the HD thing, the one that I did, they said, “Our number is always available”. And I said, “That’s what I want to hear”. I mean, I know I am going to have to go to the doctor first to say, “I might have it,” but I feel comfortable with the girls being so helpful. They listen, they kind of understand the disease. They are the sort of people I want to be going to first. Not to my doctor who hardly knows about HD, “Oh yeah, I have heard of it. It’s a rare disease, isn’t it?” I don’t want to hear those things. That’s why I’m doing that HD thing every year with the testing, so they can see any potential symptoms. They can see what your movement is like, “You are not as straight as you were last year,” you know. And that is when I start thinking to myself, “Right, they are going to be here to help now”. I don’t want to not be working. I think I would go crazy if I wasn’t working. I do not want to be a person who says, “Right, now I’m on sickness benefit for the rest of my life”. That is going to hurt me, and I know at some point if it does happen and I do get to a bad state, that is what it is going to come to. How can the state help me? How can they get me through this for the next five to ten years until the cure is out there. I keep reading, and it sounds so good what is going on at the moment.

Interviewer: I know, it’s very bubbly.

[0:15:52]

Respondent: But like most drugs, they used to take a longer period, but they have kind of shortened the whole FDA approval. I don’t know what they call it here, but they have shortened it really to help people with genetic disorders.

Interviewer: I think they have called it something like orphan drugs. So basically, they are giving it priority.

Respondent: Every chance of success, yes. It all sounds positive.

Interviewer: So, when you say you don’t want to be discussing it with your doctor, who are you referring to, your GP?

Respondent: Yeah, my GP. I don’t have an HD specific doctor yet. I don’t think I need one yet because I have got the girls to talk to. The girls, they are ample at the moment. I don’t think I need to put any more strain on a consultant HD doctor at the moment. I don’t think so anyway. You might think, “No, you should be booking yourself in”.

Interviewer: I think it sounds like you are doing these yearly reviews, which is quite a thorough review they are doing at Enroll. And as you are saying, the team in Enroll, if they see something clinically relevant, they will ask for your permission to contact the neurologist which leads the study, so that is [Name 6]. So, I was more interested if you had discussed Huntington’s with your GP?

Respondent: There was one occasion, and I think the GP was interested in it. It kind of surprised me, because she was like on a computer, because she had asked me what I do for a living, and I said, “I work with computers”. She was trying to do something, and she was like, “I can't do this,” so I said, “Let me come over and help,” and the first screen I saw was the website for Huntington’s Disease, because she had seen it on my records. So, I think she wanted me to talk about it, but I wasn’t there to talk about Huntington’s Disease. You know, I was there to deal with something else. So, I felt it wasn’t the right time to talk to a stranger, because she is just my GP, and the way GPs are now, you are happy with any GP. You don’t have a specific one anymore. It is like, “Here are the four, which one would you like to choose for this appointment that you want do to at 11:00am?” It has all changed I think now. So, the relationship between doctor and patient, client or patient, whatever they use, it has completely changed. So, you can't open up to them, whereas perhaps in the past you could. [Respondent speaking to his wife] Alright [Name 7]. I’m just on the phone with the HD people. She has just come back, sorry.

Interviewer: Can you continue talking?

Respondent: Yes, she knows everything.

Interviewer: Oh, that’s your wife?

Respondent: Yeah.

Interviewer: Oh, okay. Just let me know if … I don’t want to cause any issue with –

Respondent: No, no.

Interviewer: So [Name 2], I was quite interested in two things you said, and I want to make sure I am getting it right. I mean, it all is interesting, but I was going to ask you what would quality look like to you in terms of care, and you were saying you want to have like, financially you are concerned about these restraints.

Respondent: I don’t think I’m concerned anymore. I am too old now to invest in something huge. You know, I have got my investments, I have got this, that, and the other. So, I am happy where I am, but it is the children, isn’t it? You know, if you get tested and it is positive, then that could be a financial burden on you.

[0:20:19]

Interviewer: Yeah, the implications.

Respondent: Implications. So, don’t get tested, live with it until you are 40, and if you start showing signs hopefully someone is around to help. In the meantime, don’t let banks know, don’t let any other people know. You know, live your life, move from that semi-detached to that detached house. You know, you want to do that, you want to have that life. You know, you may not even have it, so all these gambles will be successful, and you will have the dream that you wanted. But it’s all a worry for them. For us, I think we are too old now. You know, I am not going to ask for a 35 year mortgage anymore. I am not going to ask for a loan because I need a new car. I can afford a new car. I can do all those things. It doesn’t really bother us.

Interviewer: But that is like you have thought a lot about this in terms of like what it would mean for you daughter for example, and how could you advise her the best when the time comes?

Respondent: I wouldn’t know how to advise her. That is when I need you people. I need you guys to come in and say, “We have got quite a lot of families that do have children, and some of them are even younger that you are,” and try and … she’s got cousins of a similar age that don’t know yet. My younger brother has kept it quiet from his two daughters, so I’m trying to push them together more and get them to be like the best friends ever, and you know go on holiday together. Then when it does happen, fingers crossed they are there for each other to get through it. Because it is so difficult when you have got relatives or nieces and nephews on my wife’s side in particular who don’t have anything like that to understand how bad it is. A lot of people are like that, even my work. I had to tell my manager at work, and I said, “Have you ever tried to find out what the disease is about?” and he said, “Well, I’ve heard its genetic and that’s it”.

Interviewer: It’s so much more, yeah.

Respondent: It’s so much more. He could see something and then realise, “Oh my God, he is getting very violent here. Is this a sign of his HD?” But he wouldn’t even know, he’d just say, “You’re very angry, we’ll put you through a disciplinary for doing this and saying that”. I can see that happening, at which point I might even lose my job in the process. In order to keep my job, I’d have to say, “Right, I need to open up on something. I have this disease”. You know, to the Chairman of the Board, or to the HR. And they’ll say, “What is it? What’s that? I’ve never heard of it”. And it’s like, how do you then explain something to them? I’d say, “Well, you need to talk to a professional person who will then tell you, ‘Oh, it’s to do with this, that, or the other, and you need to now help this person. You know, reduce his amount of work perhaps, not make him work as much. And you have got to keep him employed. You can't just say, “You’ve got HD, we need to get rid of you now because you are useless to us’”. It’s like, how do they deal with me?

Interviewer: Yeah, who supports you in that relationship with your employer?

Respondent: Yeah. They could say, “You just called somebody something and it’s highly inappropriate. We are going to have to let you go”. It’s something that could happen. And then I’ll know I’ve got the disease, but I’ve got the sack in the process. I can't then go back to a law court and say, “Well, I’ve got a disease. I want my job back. They owe me compensation”. They’ll say, “Well no, you didn’t tell them”. I don’t know what to do there.

Interviewer: Yeah, what’s the process here? When to tell them, and how much should they know?

Respondent: Exactly, so that I can get all the support I need when I need it to stay in that job, to continue working there. Rather than me get the sack and them say, “Well, you should have told us. By keeping it quiet you have lost your job, end of story”. Whereas if I had the job and I say something inappropriate, they will understand and will be like, “How can we make this better and say to the other person, ‘It is something that he has got. We can't explain what it is. He is not that person normally, but he is starting to become that person’”. But nobody knows anything. So, I’m keeping it quiet because I don’t want people to feel sorry for me.

[0:25:15]

Interviewer: Well, you are saying you have told your manager.

Respondent: I have told my manager, because I know him quite well. He said, “Yeah, I understand,” but I still don’t think he understands. You only get deep into something when it affects you. When it is someone else it is just like, “Yeah, it’s something hereditary. He hasn’t got symptoms so let him carry on working”. It’s the way it is, isn’t it? You don’t know the answers to all the questions, but like you say hopefully from this study you might get a few answers, and say by law now you are allowed to talk to your company and they must do everything they can, if you feel like you are having the symptoms and you have got proof that you are having the symptoms, to then say, “Yes, we knew you had it four years ago, but now you are getting the symptoms we are going to do everything to keep you in this job and try and make you work unless less pressure”. I know it can make you less multitasking and less able to handle too many problems at the same time.

Interviewer: Yeah, there is adjustments that the work can do, and should do, to keep you fruitful and productive.

Respondent: Yeah, but I haven’t told them. I have just told my manager who has kept it quiet from everyone else.

Interviewer: Yeah, but you have told him, and he’s still your manger.

Respondent: True.

Interviewer: You’ve told him. You don’t have to email the whole company. You have already made the bridge.

Respondent: I’ve made the bridge, but HR say, “The bridge is through us, not through your manager, and your manager hasn’t told us”. So, somebody needs to find that out, and you know say, “When you are diagnosed with Huntington’s Disease, HR need to then be informed, and then you are protected with all your rights”. You know, you are going to get your sickness benefit. You are going to get this, and for how long. I don’t know. At the moment I’ve not got it, and fingers crossed I don’t get it until I have finished work. But if I was to, and I lose my job because of saying something inappropriate like, “[Name 8] is sleeping with everyone in the company,” and spreading a nasty rumour around because my head has got a bit confused, it could be, “You’re out straightaway [Name 2]”. Then my manager says something, but nobody cares after that because I should have told HR. I don’t know what the policy is, and I need someone to find out. The policy should be, “You can tell HR, but they have got to keep it confidential, and they will protect you through everything”. I might have done this completely wrong.

Interviewer: I think this last week the Huntington’s Disease Association was showing, I didn’t read through it, but they were talking about a person, you know how to navigate work with Huntington’s Disease. So, the social media campaign last week was about that, I think.

Respondent: He’s opened it up to everybody, hasn’t he?

Interviewer: I didn’t go in too deep, but I know there were like videos that people could hear about how to … and I know that like you have an advisor in [Location 4], she is called [Name 9].

Respondent: I know. I did contact [Name 9] about the travel insurance, and she said, “No, you don’t need to tell anyone. You have no symptoms”.

Interviewer: Yes, exactly. I know [Name 9] would be the best person to just say like, “What do I do with work? Who to tell, and when to tell, and how much to tell”.

[0:29:00]

Respondent: Yeah, I suppose so. I’ll give [Name 9] a call. I’ve got her number.

Interviewer: I’m going to ask you just a couple of generic questions. I know we are coming to the end of our Interview and our time. So, how old are you?

[redacted]

Interviewer: [Name 2], is there anything that we haven’t covered that you would like you add in terms of what could be done better for people with Huntington’s?

Respondent: Well, my brother’s case I suppose, and now we know that he has got what he might have, but there is no help for him. There is no support for him, because he has to come forward. Rather than his doctor saying, “Yeah, it looks like your brothers got it, your sister’s got it. That means you have got it so we are going to put you on the HD expensive drug to help with this mental issue”. I don’t know if he is on the right drug, he might just be on a general drug. You know, “There’s a new one come out that can help you. It’s a little bit more expensive than the one we give to everybody, but we might think that because your brother’s got it, your sister’s got it, that you have got it, so let’s put you on that”. Rather than as the government say, “Well, until he gets tested, we are not giving him any benefits whatsoever”. And it’s torture to get tested. It’s not easy for people to go and get tested. I’m sure when the first medicine comes out, when we do have the first cure, everyone is going to start getting genetically tested to see if they have got Huntington’s, and suddenly it is no longer a rare disease, it is a common disease, and everything just explodes, and people are getting tested, “Don’t worry, there’s a medicine for it now. I’m going to get it”. And the fear just goes away doesn’t it, because you know you can get cured now.

Interviewer: [Name 2], I think there is something important to be aware of while we don’t have a cure for Huntington’s. The way Huntington’s is treated at the moment is that the symptoms are treated. For example, if a person has depression, they give them antidepressants. If a person is hallucinating or a bit psychotic, they give them antipsychotic medication regardless of being tested. So, that could be something to consider for your brother. You know, bear in mind I am not here to give you clinical advice.

Respondent: So, the doctor would have done that, would he?

Interviewer: Let’s say that his wife, they both go to the GP and say, “I have noticed that he is worried with these things that are not real, and we don’t know if he has Huntington’s or not, and he doesn’t want to be tested. How can we treat these like hallucinations or thoughts?” And then the doctor should, you know there is medication for that. So, regardless of him having Huntington’s, the specific Huntington’s medications currently are more for the chorea, so the movements.

[0:33:50]

Respondent: Yeah, that’s the new one.

Interviewer: Yeah, so that was the newly approved drug. There was already medication approved, but yes there was a recent one approved.

Respondent: Is that much better then? Is it new technology on the new way of using a drug then? Or is it a similar thing?

Interviewer: I don’t know to be honest. I know the drug has been approved. I don’t know that it has been approved yet in [Location 8]. I think it was in [Location 9]. That’s come from the FDA. I think it is Valbenazine or something.

Respondent: That’s right, yeah.

Interviewer: But it sounds more like it is these erratic thoughts that are putting pressure on his wife and your family in general.

Respondent: Yes.

Interviewer: So, I think the hard part is if he doesn’t want to go to the GP himself, how can you get him treated?

Respondent: We got him there and then I think the HD person said, “You know you don’t have to get tested? You don’t have to. We are not forcing you to get tested”. The minute they said that he was like, “Well, why am I here then? I might as well go”. It was that thing that triggered his head to say, “I don’t need to be here”.

Interviewer: Was that with the neurologist then?

Respondent: Yeah. He was going to have a blood sample. He went with his wife, everything was looking good, and then they said, “We can't force you to have this”. He thought he did. He thought, “Well, I’ve got to do it now because of this”. They said it to me. They said, “You don’t have to do this,” and I said, “I’d like to do it, because I need to know”. That was my response. His response was, “Let’s go. I don’t need to do this”. I don’t think his mind was in the right frame of mind to answer that question.

Interviewer: That’s why I’m saying he can still get treated without the test. That’s why I was thinking that going via the GP, even if the wife makes the connection to say, “He doesn’t want to get tested. We can't force him”.

Respondent: But like you say, it is going to make no difference really. He is still going to get the same medicine. There is nothing at the moment out there that has been approved.

Interviewer: Yeah, so there is no Huntington’s Disease specific drug. What there are is drugs to treat the movements, or drugs to treat the cognitive part, the thinking part, or the hallucinations part, the depression, the low mood. So, there is drugs for that independently of him testing positive. So, I think if he can't do that for himself, as it is hard, he is an adult, grown man, to make people realise, “Well, he doesn’t want to, so why would we pursue this?” It could be that he understands that you are saying these things and are worried. I am not sure if his wife can somehow convince him to go to the GP, not to the geneticist, but to get treatment. You know, if he doesn’t want to know that he has Huntington’s he doesn’t really need to. The genetics, they will never force him, so he will always leave like, “Oh, I don’t have to, so I’m leaving”.

[0:37:53]

Respondent: That’s what he keeps thinking, “I don’t have it,” but everyone around him can see that he has kind of got a problem. In his mind there is nothing wrong. Which is what Huntington’s is like, I think. You get angry. A little remark and he gets angry. It’s a tough one. I don’t know what to do.

Interviewer: You know, you said you have [Name 9] number, and [Name 9] is an expert, and she’s used to doing these links between the GP, and the geneticist, or the family, and being cautious. That is what she does all the time.

Respondent: This is all in [Location 10]. So, they are all in [Location 11]. My brother is in [Location 5]. I am just in the south, [Location 12].

Interviewer: Yeah, they have the equivalent of [Name 9] there. So, on the Huntington’s Disease Association, on the branches, you have … I’m not saying you, but if his wife for example wants to reach out to an expert there.

Respondent: She’s worked for the NHS for so long, so she knows all the experts in the [Location 10] area, because she knew them all, hence the reason she fast-tracked this to get him into that room to get his blood test. It was really easy for her. She knew what was going on. She talked to loads of people that were in the f. She made a specific push to try and get him in and get tested. It was just that one response when he said, “You don’t have to get tested,” and he was gone.

Interviewer: Yeah. It must have been very frustrating, but I don’t think there was another way for them not to say it.

Respondent: But if he’d got tested, he might have realised, “Yes, there is something wrong with me…” and apologised for all the things that he said, “…and now I’ve got to sort it out in my head that these things aren’t true, these things aren’t happening. It’s my head going around, and now I’ve got to control it, now I’ve got to keep smiling and not worry”. I think he is going too far. I think he is losing his mind. No-one can get you back the further you go on and start losing your mind. Everything becomes real. A dream possibly becomes real. He’s in a state where he wishes he never had those symptoms and then he could have dealt with it and then controlled it later on. At the moment I don’t think anyone can reason with him. I don’t know how to get to him without getting him angry and him saying, “I don’t want to talk to you anymore. I don’t need you”. He said, “I’ll come and live with you for a while”. I said, “I’ve got my wife and I’ve got my daughter I can't have you living with me. It doesn’t work like that anymore. I’ve got a marriage here, and this is the woman who is potentially going to take care of me if I do go downhill. I can't be adding more and more stress to her for her to say, ‘Look, I can't live with this, bye’”. I mean, I hope she never says that. Hopefully she won’t. She’ll be with me until the end, but you know I don’t know how bad this can become for a woman to say, “Look, this is just too much for me. Can we put him in a home? Can we put him away somewhere?” You know, you don’t know. You don’t know how it can push somebody from loving somebody to –

Interviewer: No, and usually when people don’t accept help, as you as saying, what happens is it ends up that it needs to come to a crisis moment where they are sectioned, which means that then the health services understand that he has no capacity to make a decision of what is best for him, and then they intervene.

Respondent: That’s when he does something stupid.

Interviewer: Your sister-in-law might need to speak alone with the GP to discuss these things. Or with the Huntington’s advisor there, because they are unfortunately used to this. It is sadly quite normal for people not to accept. You know, they don’t see it the way we do, so it needs to be controlled for them because they can't do it themselves.

Respondent: Yeah, that’s the trouble, isn’t it?

[0:42:31]

[redacted]

[End of transcript]