[0:00:00]

[redacted]

Interviewer: Yeah, good. So, the first thing is really for you to tell me about your work, so I just wanted to make sure consent part, that you’re happy. So, you’re saying you work for the integrated care board.

Respondent: Yeah, so [location 2] and [location 3] integrated care board, so we look after the health-funded patients. So, you know with…

[0:04:28]

Interviewer: Did you say the well-funded patients?

Respondent: The health.

Interviewer: Oh, the health-funded.

Respondent: Yeah. So, in England, you probably know, so we have two streams of funding for patients who have needs. So, we have Social Services who fund some patients and then obviously we’ve got continuing healthcare and we fund the patients who are much more complex. We’ve got like a health element within that. So, for example, somebody with Huntington’s, it doesn’t mean that we would fund them from straight away, so it could be that their care starts with social care because actually at the earlier stages of the disease, they might be coping quite well. You know, there might not be any medical kind of issues going on with them. But as they deteriorate and when they get to that stage where everything’s affected, their swallowing, their mobility, absolutely everything, then we take over the funding.

Interviewer: Alright, okay. Here I was thinking you were… I mean I did see CHC in some, yeah, that’s it. This is great for me. I’m very pleased. So, how often do you see or do you have… what sort of contact do you have with people with Huntington’s then?

Respondent: Okay, so like all my patients, including the Huntington’s patients, I usually get a referral or the patient’s family sometimes contact me if there’s issues going on that they need me to look at. So, this with kind of particular patient, I think I had a referral from one of our own nurses, because our nurses do a review every 12 months to make sure that people are still eligible for NHS funding, and they do that assessment every 12 months. And during that assessment they pick up any issues and things, and if they pick up that there’s any issues with equipment or anything like that then they’ll make a referral to myself. I will then contact the family or the patient, go out and do an assessment to find out what the issues are, and then I’ll have a look at how we’re going to resolve them. So, for example, with this young lady I have been involved with her quite a lot of times because the deterioration, certainly within the last 18 months, has been very rapid. So, she’s had the chorea movements and they’ve been… the chorea movements that she’s had have been so bad that even the consultant said he hadn’t seen anybody quite that bad. So, she’s broken a tilt-in-space armchair, which are quite strong. She’d got pads all around her bed and her legs and her limbs were going over the bed and she was banging herself onto the bedrails. So, then we had to have some special padding made, which was probably about, oh, about 20 inches high above, so it went above the bedrails, and they were really, really thick, so we had to have those specially made for her and fitted onto her bed. So, it’s about keeping her safe and looking at what equipment we need to provide or what we need to make for her to keep her safe.

Interviewer: So, [name 1], you go to people’s houses…

Respondent: Houses, yeah.

Interviewer: Or whenever they are, I guess.

Respondent: Yeah.

Interviewer: They’re not always in their own homes, I’m assuming.

Respondent: No, they might be in a nursing home. Yeah, they’re likely to be either in a nursing home or in their own home. But mostly I find that they are at home.

Interviewer: And when you get the referrals, who’s referring the patients to you?

[0:08:23]

Respondent: So, it could be our nurses that does the 12-month review, or it could be the patient’s family.

Interviewer: So, they can self-refer.

Respondent: Yeah, or even the carers. So, if they’ve got a package of care, sometimes even the carers ring me up and say, “Look, we’re having this problem”.

Interviewer: Okay, so they would have your card or… I’m sorry, it’s just like I’m really trying, in terms of the logistics, how do they know that you exist?

Respondent: So, the first time, they will contact their nurses. So, they’ll have a named nurse, they have they call a case worker.

Interviewer: And this is in the NHS in the [location 3] and [location 2]…

Respondent: ICB, yeah.

Interviewer: ICB, yeah. Okay, they have a case worker.

Respondent: Yeah. So, they’ll know who their case worker is, so they’ll contact the case worker and the case worker will then do a referral. After I’ve been to them the first time, they often say, “Can we have your phone number?” and I say, “Yeah, that’s absolutely fine”. And once they’ve got my phone number they just ring me directly.

Interviewer: Yeah, yeah. And the case worker is usually a nurse?

Respondent: Yeah, they’re all nurses.

Interviewer: They’re all nurses.

Respondent: Yeah, because under continuing healthcare, if you look at the legislation, it has to be a nurse, it says, on the legislation, who has to do the reviews.

Interviewer: And the CHC nurse falls under your team directly?

Respondent: Yeah, yeah. They’re all part of the team. So, I’m part of the continuing healthcare team, CHC team.

Interviewer: So, there’s nurses, there’s you, and is there anyone else?

Respondent: No, that’s it. So, I joined this team just before… about [year], round about then, just before Covid, before that they didn’t have any OTs, they just had the nurses. So, if they needed an OT previously they would then have to refer to the community services. And they had a contract with the Social Services’ OTs and they would come out and do the assessment. But what they would do is they would just look at that one single issue, whereas when I go out, I do what I call a holistic assessment. I look at the whole picture and deal with all of it, even if it takes me, I don’t know, six months, a year, even if I’m involved for a long time, I will not close that case down until I’ve dealt with it. So, this young lady that I’ve got, she’s probably been open to me now for about 12, at least 12 months, and I won’t close the case because I know that there’s going to be ongoing issues coming all the time and I know that her mum will just contact me, whereas before, when they had the contract with social care, they used to come in and just deal with that one bit and that’s all they would do. So, they employed me and they made me permanent in [year].

Interviewer: So, what’s the feedback you’ve got since you’ve been, well, you’ve been kept, because that’s a big difference from… I mean do you have patients giving you some feedback or your colleagues? I’m assuming the difference was very positive otherwise they wouldn’t have, you know, employed you.

[0:11:42]

Respondent: That’s right. Yeah. That’s what they said. They said that I made a big, big difference. The nurses felt that to have their own OT within the team was very, very positive as well because they can talk to me for advice as well and I will give them advice, especially some of the new nurses who aren’t quite sure what they’re doing, I kind of support them. And then any equipment, I can give them training in regards to what equipment’s available, how they can get hold of it, so when they go out and do their reviews, they’ve got a good idea of what we can do. And I always say to them, “If you’re not sure, just ring me and talk it through”.

Interviewer: And you’re employed full time?

Respondent: Yeah, I’m employed full time at the moment but I am going to drop some hours in July.

Interviewer: Okay, okay. Do you know if the hours will be taken, like…?

Respondent: I think what they’re thinking is I think they’re thinking they might employ an OT assistant, but I don’t know what they’re going to do. But I have said to them the kind of patients we deal with, they are very, very complex. I really feel that you need a qualified person.

Interviewer: That was my next question, how did you… so you said you have your OT degree and you’ve done your master’s, and at what point do you get contact with Huntington’s patients, like in your profession? As in throughout time, when did you… how did you develop this knowledge in Huntington’s disease?

Respondent: Well, as an OT, I’ve been qualified for about [20-30] years and I’ve worked in lots and lots of different areas, so I worked in [location 4], [location 5], [location 2], back to [location 4], [location 6], and then at the [hospital name], at the hospital, acute hospital, and then obviously back here, the integrated care board. So, I’ve worked in lots of different places and I’ve done a range of different jobs really, from working in the community, I’ve worked in Social Services, I’ve worked in an acute hospital. And throughout that tine I have seen a range of obviously different disabilities, including Huntington’s, and you kind of pick up your expertise and your experience when you’re working with patients really.

Interviewer: Okay. So, it’s pretty much you have a life’s worth of experience that prepares you.

Respondent: Yeah, the experience definitely helps.

Interviewer: What, sorry?

Respondent: Yeah, I said the experience is really, really important because I find that when I’m working with some of the OTs, for example, they’ve only ever worked in one place and I think that limits your experience, whereas I think if you’ve had a range of different areas that you’ve worked in, I think that definitely helps with your experience with lots of different disabilities, including Huntington’s.

Interviewer: And now that, especially now that you’re thinking of dropping your hours, how… I don’t know if it’s your responsibility, but are you thinking of how will you train someone to take part of the caseload when you’re not there or does that exist already? Because you said you do a holistic assessment, for example, so is this… do you have a template? How do you structure your assessments?

Respondent: For the assessments? So, I have what I call an assessment form that I use. So, I kind of… we have a system called [electronic system], and all the clinical information is on there. Our nurses have done the 12-month review, all the information is on there. So, when I get a referral, I look through [electronic system] and try and get as much information as possible in terms of their disability, functionally how that’s affecting them, what equipment that they’ve got, whether they’re mobile, how they’re moving around, all those kinds of things really. So, I try and pick up as much as possible, and then I take my form, my rough copy form with me to go and see the patient and from then I can get further information in terms of, you know, what I need to know in terms of what the issues are, and then I kind of discuss those with the patient or the family member in terms of what the difficulties are. We talk about what the options are in terms of how we could resolve the problem, and then try and meet halfway in terms of what’s acceptable for the patient or the family and what I can provide as well.

[0:16:38]

Interviewer: And the [electronic] system, who can access this?

Respondent: All the clinical staff, yeah, and the admin staff actually, yeah.

Interviewer: The clinical staff within your team?

Respondent: Yeah.

Interviewer: Or, for example, would the patient’s GP be able to see that?

Respondent: No, they wouldn’t. So, at the moment all the systems seem to be separate. So, for example, if they’re in hospital, I can’t see their systems, they can’t see our system, and if somebody in the community goes to see them, I can’t see their systems. So, it’s a case of just trying to communicate with as many people as possible.

Interviewer: And is that easy?

Respondent: No, it’s not easy at all. So, obviously you rely a lot on families to tell you what’s happened.

Interviewer: Okay. Do any of your patients have like an app, like access to their medical records…

Respondent: No.

Interviewer: Even like from the hospital? That’s not something…?

Respondent: No, that doesn’t happen, no.

Interviewer: Okay. Do people complain of this or this…?

Respondent: Not… yeah, I don’t know. I suppose they do, but yeah, it’s just not possible. They might get a letter, you know when they’re discharge from a hospital, they might get a letter that goes to the GP and that might be about it, but yeah, in terms of accessing your NHS notes, no. When the nurses go out for assessments every 12 months to say they’re still eligible because they meet the criteria for our funding, obviously families are invited to that and they go through all the checklist in terms of the questions, so I suppose they have some input there so they know. And our nurses will also contact the GPs and get a GP record for the last 12 months as well so that they can see if they’ve… how many times they’ve been to see the GP, any illnesses, if they’ve been admitted to hospital, that’s usually on the GP records. That’s about it really.

Interviewer: Okay, so the nurses when they go do these assessments, they spend some time checking what’s happened in the last year.

Respondent: Yeah.

Interviewer: Okay. And do you think this is the optimal way of having to… so basically we’re relying on families telling the professionals what happened in the last year.

Respondent: Mmm.

Interviewer: Because we can’t see what’s on the… well, on the other… the system of the hospital, the system of the GP. Does it happen that there’s missed information or…?

[0:19:34]

Respondent: I think it is difficult for the nurses because they have two hours to do that assessment and so to get to know somebody really, really well, I find that when I go out and see somebody for the first time, sometimes it takes a few visits before you build up a relationship and that rapport with that person or with their families before they trust you. And so to go out and do that as a new person where you’ve never met that person, or sometimes they don’t even go out, sometimes they do it online in a Teams meeting, and I always say, “I don’t see how you can assess somebody in Teams. You need to go out and see them. You need to actually see how they are presenting, how they’re mobilising, you know, what the issues are before you can actually appreciate what the difficulties are for this person,” because during Covid the nurses didn’t go out at all, they just did it via Teams.

Interviewer: So, did this stick then, the…?

Respondent: I think they just… I think what they did was, you know, the information that they had from the 12 months before, I think they just kind of kept that information and so they just said, “Oh, nothing’s changed. They’re still eligible,” so that’s how they did it. And now that we’ve come out of Covid and I know that they’re doing more face-to-face assessments, and I think they’re finding that some people who probably met the criteria before, not Huntington’s patients but other patients, probably don’t meet the criteria any more so the funding’s been stopped obviously for some people. But you’ve really got to go and see that person, you know, to be able to appreciate what the difficulties are, especially if they’re deteriorating, like the young lady that I’m working with currently that I just keep the case open because I know that every now and then there’s going to be an issue.

Interviewer: And it will tend to get worse as (overspeaking).

Respondent: Yeah. And you don’t want to put the family under any stress, so you’re just ready to kind of listen to what the issues are and then think about it.

Interviewer: I’m sorry, my dog is really misbehaving. What are you doing? He was making so much noise and he’s just like a little dog. So sorry.

Respondent: That’s alright.

Interviewer: Can you behave, please? Because if I lock him out, he’ll start barking and it’s just even worse. That’s what it is. Okay, okay. I wanted to ask if you’re happy with the sort of support you’re providing.

Respondent: I like to think so. So, you know, if I kind of get a really, really complex issue where I’m trying to deal with it, and sometimes the family members’ expectation sometimes is really, really high, you know, so what do I do in those circumstances? I’ll contact [name 3] and see if she’s got any ideas. So, we try and share the load really and then use that information to try and come up with a plan after that. But I usually find that when I do that, she usually comes back to me and says, “Well, you’re doing everything right anyway”.

Interviewer: Yeah, it’s just looking, I guess, for a bit of reassurance, isn’t it, sometimes that… yeah.

Respondent: Yeah, just in case you missed anything really, so yeah.

Interviewer: So, [name 3], so [[location 7], because I guess it comes up as the expert centre, that’s why you turn to [name 3], because she sees a lot of patients, well, her patients are all Huntington’s.

Respondent: (overspeaking) yeah. And you can say to families as well, you know, so it gives them a bit of confidence as well that you’ve kind of spoken to the experts, as it were, and they can’t think of anything else that you’re not already doing. Some families think, you know… I think with this young lady, when I first became involved she said to me, “Have you ever worked with patients with Huntington’s?” That was the first thing she said, and I think that spells it all out, doesn’t it? If they’ve seen lots of professionals and they’ve never had anything to do with anybody with Huntington’s, you can see how their confidence would be affected.

[0:24:07]

Interviewer: Yeah, yeah, no, I see that a lot as well, which is understandable, isn’t it? So, do you have more patients currently? What would be your caseload for Huntington’s patients?

Respondent: So, altogether my caseload is probably between 30 and 40 that I carry that are open cases to me. So, in terms of Huntington’s, I haven’t got that many. I’ve probably only got about four patients with Huntington’s at the moment, because usually what happens is once I’ve dealt with whatever the issue is or they haven’t got any other needs, I then close them down.

Interviewer: Yeah, yeah, and they stay with your contact, as you say, so they can…

Respondent: Yeah, I usually find the family members usually then contact me if there’s an issue with the piece of equipment. So, in terms of Huntington’s, you know, as an OT, it’s more around equipment really that I get asked to support with. So, it’s usually things like obviously protective beds, you know, so when they’re bashing around they’re not hurting themselves, or tilt-in-space chairs that we can kind of position them properly for feeding and for sitting out. Things like manual handling to the carers, so lots to do with hoists and slings.

Interviewer: Oh, that’s great. So, you provide that…

Respondent: We’ll provide anything that…

Interviewer: Training for manual handling to carers?

Respondent: Yeah, and advice for them as well. So, somebody with the chorea movements, so the young lady I had, her chorea movements were so bad that when they were trying to put the slings on her, her limbs were going everywhere and she was hitting the staff because of the movements. And so I had to have a look for a sling, because obviously she wasn’t comfortable in the sling. She wasn’t very comfortable being hoisted, so we had to have a look at why do her movements increase? What is it that’s making that? And I thought I’m wondering whether she’s not very comfortable in the sling that they’re using, you know. What is it that they’re doing. So, I brought a rep in and we had a look at a sling and the sling that they’d put her in, she didn’t look very comfortable in at all. She was like leaning backwards.

Interviewer: Oh, she was like she thought she was going go fall.

Respondent: Yeah, she was like this and it was kind of like, okay, so yeah, so I thought she’s obviously not comfortable in it. So, we tried her in a couple of different slings and we found the one that was really, really suitable for her because we put her in it, they hoisted her up just above her bed, and she sat in that sling like that without moving, no limbs moving, for about ten minutes. Her mum was there. Her mum said, “She’s obviously comfortable because she hasn’t done that, you know, she hasn’t moved or anything. She looks really, really comfortable”. There were no limbs moving or anything at all, and that resolved the issue for the carers that they could then hoist her.

Interviewer: Yeah, what a difference.

Respondent: Yeah, it did make a difference. And that’s what I find, you know, it’s usually trying to identify what it is that’s affecting their behaviour and what is it that I can provide that’s going to make them safer, more comfortable and make it easier for the carers as well.

[0:27:58]

Interviewer: Yeah. So, when you can do this, when you can see this sort of difference, of course you know you’re making a… you’re doing a good job, right?

Respondent: Yeah, making a difference, yeah, definitely.

Interviewer: Yeah. That’s reassuring. So, do you have difficulties in your job, [name 1], with linking with other professionals or in terms of coordination. I mean I can see you have those case workers. I’m not sure who takes more on that, or if it’s just plenty for all of you to do in terms of coordination, linking with other professionals, what’s easy, what’s hard?

Respondent: I think once people find out that somebody’s funded by continuing healthcare, it’s like hands off. It’s like, “We’re not going to do anything because they’re funded by health and so health can do it”. I find that attitude an awful lot. Yeah, so, for example, if somebody has an urgent need and they need to be seen and the community team… because I don’t do urgents. I can’t do urgent cases, so if somebody called in today, I couldn’t go out and see somebody on the same day or even the next day sometimes, you know, because of my limitations. So, the community team have to go out, and I find that the community team’s attitude is not very good. And all they want to do is pass… sorry, all they want to do is pass the case on because they’re funded by continuing healthcare.

Interviewer: And why is that? Is it because being funded by CHC means patients are too complex, or is it because they’re like, “Well, you’re the ones funded to do that, so you deal with that”.

Respondent: Yeah, that’s it. That’s definitely the attitude I kind of get, yeah. “We’re not funding it so we’re not going to do it,” whereas I always say to people, “It doesn’t matter who’s funding it, if you need some advice, just ring me”. It doesn’t matter if we’re funding the patient or if we’re not funding the patient, because quite often people will come to me and say, “Oh, I’ve got this patient,” and I look on our system and I think, “Oh, we’re not funding them”. But I don’t say, “We’re not funding them, we’re not going to do anything”. I’ll still give them advice but it doesn’t seem to work the other way around.

Interviewer: So, where do you think this comes from? You know, on the other side, of course you’re not part of the other team, but say you’re in the community team, there’s a new member starting, do you think… surely it doesn’t say on their stated demands, you know, “Don’t help if it’s not…”

Respondent: But it’s an attitude, isn’t it? It’s an attitude that people seem to develop when they’re in different teams and it seems to be us and them all the time, that’s what I find. That, yeah, that if they’re not funding it then they’ll do the bare minimum. So, for example, if someone’s got an emergency, community team will go out. So, I had somebody recently, the community team went out, they gave them a commode and that was it. That was all they did. And when I picked them up to kind of check what had been done, I was kind of like, you know, what’s the use of just giving them a commode? Their mobility deteriorated, so in December they were walking, in January they weren’t walking, so I’m looking at the bigger picture and thinking, well, what’s happened to their mobility? Is there something medically wrong with them? What’s happened? They really need to see physio to get them moving again because if they were walking a few weeks ago and now they’re no longer walking or they’re having lots of falls, there’s something going on. So, I try to dig deep to try and find out and deal with it and make all the referrals to all the relevant places. I’ll write to the GP and ask them to do a referral to physio, for example. But yeah, but the community teams tend to do the most minimum and that’s it.

Interviewer: So, it seems like quite acute, because you may have an individual doing, you know, all they can, which sounds like it’s your case, but then you have the community team, which should be quite a strong link because, as you’re saying, you’re not doing 24/7 assistance, and people are just getting worse until you get the time to then attend. I mean what could be done better then in relation to this? What would be helpful?

[0:33:29]

Respondent: I mean for that case, we’ve talked about seamless working, haven’t we? We’ve talked about all the teams working together, having one system so that you can see each other’s notes and systems and things, and that hasn’t happened and yet we’ve been talking about it for absolutely decades. If you look at all the legislation that the government’s put forward in terms of joining everybody up, I don’t know, I think it’s an attitudinal thing really. I think sometimes people do the minimum in their job, whereas I probably do the maximum, you know. I probably hang onto people to make sure that everything’s kind of sorted for them before I close the case. And being in this job, it enables me to do that, so nobody questions me how I’m spending my time, how many times I’m going to see anybody. Nobody questions me, and I like that because it means, you know, I have standards, so I’m an OT, our body, the British Association of OTs, we have rules that, as the nurses do in terms of that they have to work… standards that they have to work to, and I work to my standards and, yeah, and I’m… and for me, that’s really important for me to work to the standards, and not everybody does, but I’m really lucky with my managers. They kind of leave me to it. They trust me to do my work and I do that.

Interviewer: But, [name 1], the community team goes under the ICB as well, right?

Respondent: No, they don’t. No, so the community team are funded by Social Services, or if they’re in hospital then the NHS, but it’s not the ICB.

Interviewer: I mean it’s quite… because it’ s a new structure and I’m not sure that the whole country is… what constitutes an ICB and an ICS is the same, or ICB and ICPs is the same in all the country, I’m not sure. As far as you’re aware, it’s normal for the community team to be out of the… not part of the ICB.

Respondent: No, they’re not part of the ICB. I mean we are going to be moving, so, you know, we are moving towards the community and I think later this year or perhaps next year they’re going to move us into the community teams and then we’ll see how that works. So, whether then once we’re joined up whether then they’ll do social care and ICB work, I don’t know. I don’t know how that’s going to go. I don’t think anybody knows what’s going to happen yet.

Interviewer: Because that’s, you know, a big funding shift then.

Respondent: Yeah, there’s a lot of change going on at the moment. So, previously, in terms of the Integrated Care Board, we were providers and commissioners, whereas the new legislation says that the ICB can’t be commissioners and providers, and so that’s why they’re splitting us. So, that’s why all the providers, like all the clinical stuff, are going to have to be moved, and I think we’re either going to… I think half of us are going to go towards the community team and the other half are going to go to [hospital], to the acute hospital teams.

Interviewer: Do you think that will be better?

Respondent: I don’t know. I suppose until we move and start working there, I don’t know whether that will be better or not. They might start saying, “Well, why are you spending so much time with certain patients?” I don’t know, I don’t know. I mean at the moment I can spend as much time as I want to make a difference to that patient and I’ll stay with them until I’ve resolved it. So, for example, if I’m providing them with a specialist piece of equipment, say, for example, I’m going to provide them with a specially made sling for them that’s bespoke, so obviously we’ve got to go out with a rep and get all the measurements to get a sling. Then we’ve got to get a quote. Once we’ve got a quote, we’ve got to get authorisation to get it authorised and paid for. And sometimes these slings cost £500 or £600 for one, and I never buy one, I always buy a minimum of two, sometimes…

Interviewer: Yeah, because they get dirty.

[0:38:16]

Respondent: Yeah, sometimes three, so if they’re having a shower then they need an additional one, so, you know, it’s a lot of money, isn’t it? And then obviously once we’ve got authorisation, we then have to order it. Once it’s been ordered it’s then delivered, so you can see the system can take quite a long time from start to finish to get that specialist piece of equipment. It can take four months sometimes, quite a long, long time, so depending on what it is and what we have to have specially made. But yeah, so when we’re moving to the new system, I don’t know how that will work, whether the system will even more complicate it because it’s a bigger system, whether it will take even longer to get specialist equipment in. But for people with Huntington’s who are deteriorating, you need that equipment now. You want it quick, you know. You can’t be waiting months and months.

Interviewer: Do you have limitation on how much equipment you can order or how much can you spend per patient or…?

Respondent: No, not really. So, once I’ve done the assessment and I’ve identified what the issues are, and then obviously identified the equipment that’s going to meet their needs, I don’t have any problems getting authorisation. The managers are really, really quite good. They trust me and they just sign it off and then we provide the equipment.

Interviewer: Okay. So, are there specific things that your patients complain about in terms of… because you build a rapport with them, you see them many times, do you get regular complaints of people, like about the system?

Respondent: Yeah, I mean I’ll be honest with you, in terms of OT, I do get lots of positive feedback from people. But I think in terms of the system in terms of what nurses do in terms of their assessments, you know, I do get some negative feedback about that when people are saying to me, you know, “They haven’t come to see me personally”. They’ve done it on the phone or they’ve done it on Teams, and, “How can they understand what the needs of my daughter, my relative is?” so I do get lots of those kind of complaints. Sometimes when equipment’s delayed because the organisation that we’re getting it from obviously can take a long time, we do get complaints about that and I have to say, “Well, once I’ve ordered it, it’s out of my control. All I can do is keep chasing the company who’s providing that, keep chasing up to say when are we going to get it”. So, a lot of the equipment that we have to order has to go through a company called [company name], so we have these equipment stores where they have standard equipment, but if we need specialist equipment we have to order it through them. And that causes a lot of problems because we get lots of delays. So, once you’ve ordered the equipment on their system, they have three or four different systems to go through before that equipment’s actually ordered. So, what I try to do is I try to keep abreast of whether it’s been ordered from [company name] or not, so I’ll ring the company and say, “Have you had the order yet?” to try and push it along, and if they say no, then I get back onto [company name] and say, “Look, I need this equipment urgently. Can you order it?” But yeah, it’s like one system to another. It’s just everything slows down. And at the moment I’m having lots of problems with [company name] because a lot of equipment is on hold and so lots of companies aren’t getting paid, so they’re not getting paid so they’re not going to order the equipment. And I’ve told my manager that, that [company name] are putting lots of orders on hold.

Interviewer: They’re not getting paid by the NHS?

Respondent: Yeah, they’re not getting paid by [company name] and so the equipment’s not even being ordered. That’s a big problem for me all the time, how long it takes to get equipment. Sometimes if you’ve got somebody that lives in [location 3] that needs equipment, they haven’t got an equipment store they can order it from so then it has to go through our finance team, so then they have to raise a purchase order, and that always gets lost somewhere in our financial team somewhere, who are based somewhere in [location 8], about 300 miles away. Yeah, and then I’m constantly chasing. So, I spend a lot of my time chasing orders that I’ve made, trying to find out have the company been paid or not, because if they haven’t been paid then we know I’m not going to get it. That’s a big, big issue.

[0:43:30]

Interviewer: And you don’t know why they’re not getting paid.

Respondent: Well, with our finance team, again, lots and lots of complications. If there’s something wrong on the quote, say they have raise a purchase order and we send them the quote, if there’s anything wrong on the quote they seem to just stop it. They don’t contact you and say, “Actually, there’s something wrong with that quote”. For example, the company have used a patient’s name. We can’t have anything with the patient’s name on, so instead of coming back to you and saying, “We need to get that quote redone and take the patient’s name off,” they just seem to stop it and it seems to get stuck in the system, and it’s not until I chase it to find out what it is, then somebody says, “Oh, yeah, we stopped it about five weeks ago. It didn’t go through”. “So, why didn’t you come back and tell me?” They don’t.

Interviewer: You don’t have any administrative staff?

Respondent: We do, we do, and I email them to chase it up, but yeah, it still doesn’t get any further. That’s one of my bugbears, I’m afraid.

Interviewer: Yeah, yeah. Okay, it sounds like… yeah, I mean you’re extremely well qualified to be spending time chasing this, but it sounds like if you don’t do it then it will never come.

Respondent: Yeah, and that’s how I see it. If I don’t chase it, it won’t get done. It’s not my job to do it, but I do it.

Interviewer: Yeah, in the best interest of the patient. Yeah, okay. Alright. Okay, so I apologise because I’m not quite 100% today. I have a massive migraine so I’m a bit slower than normal, just so that you know. I’m usually a bit better with my thinking.

Respondent: That’s fine.

Interviewer: Okay. So, in terms of… this is always a tricky question to ask. I find it hard to phrase it. What I want to know is if the system was working well, and by well I mean better linked, you know, if the teams were better coordinated, what difference would families or patients see?

Respondent: I think the families would see a big, big difference because they would get their services a lot quicker. They’d be a lot clearer in terms of who they could contact for help.

Interviewer: So, is that not even clear like with the system as it is, with the case workers and with you giving your number?

Respondent: I think with the case workers, it’s always difficult because the case workers, they change them from time to time and so if the case workers only see them the once every 12 months, the patients or patient’s families don’t always remember who that was, because remember, they might have only seen them once 12 months ago and they can’t even remember who the name is, so I’ll say to them, “Oh, yes, your case managers was Mrs Smith,” or something, and they’ll say, “Oh, was it?” because they don’t really see them. So, if there’s a problem they might ring in and speak to duty, so, for example, if you’ve got somebody who’s deteriorating and they need to extend their package of care so they need more hours, so they will ring in, speak to duty and duty will sort it out. So, it’s not necessarily their case manager, so they might not even remember who their case manager is, whereas for me, when I go out and see them, they’ll see me a minimum of twice, or somebody with Huntington’s, yeah, will get to know me, I’ll have been numerous times dealing with lots of issues because quite often with Huntington’s patients, I deal with one problem and then I recognise another one, deal with that one, then another one, and another, and it kind of goes on. So, I had a gentleman who was discharged from hospital and they discharged him and the ambulance people carried him upstairs, so he was isolated upstairs. Couldn’t come down the stairs or anything, and he was just upstairs all the time. And his wife had been in touch with [name 3] and another OT that works at [hospital], who deals with Huntington’s patients. And I didn’t know that they were involved at the time, but she contacted me and said, “Look, I really need to get him down. He’s isolated upstairs by himself. Can we get a bed downstairs?” So, I said, “Yeah, yeah, sure. That’s not a problem at all”. So, I kind of ordered another hospital bed and we had it in the living room and I ordered what we call a gantry hoist that went around the bed downstairs, and I got the ambulancemen to come and bring him downstairs.

[0:49:00]

Interviewer: Move him.

Respondent: Yeah, to move, to carry him downstairs, to put him on that bed because it was the only way. And when I spoke to the Huntington’s OT, she said, “How did you do it?” I explained it to her, and she said, “Oh,” she said, because the wife had been asking her for ages but she couldn’t work out how they were going to bring him back down. And I said, “Well, I just ordered the duplicate equipment that he had upstairs downstairs and I had the ambulancemen come and carry him downstairs and he's now downstairs”. And then once we’d got him downstairs, the wife then had an extension built on the side of the house so she had a wet room and a bedroom, so then we had to do all the same again, so then we had to order duplicate equipment to go into his bedroom with a ceiling track hoist, and then once that was done, we kind of then moved him from the living room into… yeah.

Interviewer: Yeah, wow.

Respondent: Yeah, so that probably went on for about 18 months, to be honest, by the time they’d finished the extension, by the time we’d got the wet room in. And then once he’d got his wet room, he needed a specialist shower chair, like a tilt-in-space shower chair, so we got that sorted. Then his wife wanted him to be able to sit out in a chair, so then we had to sort him out a tilt-in-space armchair so that they could then hoist him. But she’s not contacted me for ages now so I’m assuming that they’re managing with everything, yeah, with everything I’ve done. And that’s what I try to do, try and sort them out so then I haven’t got to keep inputting into their private lives because what you don’t want is you don’t want professionals keep coming in, doing a bit here, doing a bit there. You might as well just go in and sort it all out and then you can just move out and then think, right, that’s it, you know, they can... yeah, they can manage.

Interviewer: So, what really is the definition of the case manager then? Because what patients usually ask is that they want someone that is an expert and knows what they’re doing, but continuity, so they want to see the same person. I mean to see the same person once a year, it’s the same person, but does the person know them, like know their…?

Respondent: Sometimes, they might have a case manager, but when they come to do the appointment at 12 months, they might not even see that case manager. They might allocate it to a different person, because if that case manager hasn’t got capacity, then they will allocate it to a different person.

Interviewer: See, that’s so strange. For me that’s not a case manager.

Respondent: No, but they call them case managers, and they’re supposed to case manager, but they don’t. I think I do more case management when I start dealing with them.

Interviewer: Yeah, it sounds like it. I mean, yeah, I’ve been thinking this since the beginning of the interview that basically you’re doing the case management, because you’re doing the holistic assessment, you’re looking after their needs, you’re proactively checking if the goals are being met.

Respondent: And I’m checking their care packages as well, so I’m talking to them about their carers, are the carers doing what they’re supposed to be doing, have you got enough care in, you know, and if there’s any concerns around the carers, for example, then I will put in what I call a concerns form. So, obviously some of the carers, you know, they all should have manual handling training, and I’m sure they do manual handling training, but some people are better at it than other people. So, sometimes I pick up risks and concerns, and obviously, you know, because I’m case managing for that period whatever their needs are, I then have to put those in as well.

[0:53:01]

Interviewer: So, these concerns form, what does it entail? What do you do with it?

Respondent: That goes to our commissioners then, so the people who are commissioning the care. So, the agencies that we use, the carers that we use, obviously they belong to certain agencies and they have to be credited, if there’s a concern then that has to go to our commissioners and then they have to investigate it to find out what the issue was. And if the carers are doing something that’s not safe, obviously they then have to have retraining. And if the concerns are being picked up with one agency a lot, then the commissioners have to think about, you know, do we actually commission this service, this agency?

Interviewer: Ah, so like for formal carers.

Respondent: Yeah.

Interviewer: So, okay, I understand. Sorry, I was thinking about the relatives, the carers.

Respondent: No, no, no, not the family. Yeah.

Interviewer: You’re talking about the formal carers, yeah, the agencies. Yeah, I just got you.

Respondent: That’s right. And some of the packages that we’re paying for, you know, some of those packages are costing us £5000 a week, so we’re talking over £100,000 a year for these agencies, because, you know, with the Huntington’s patients, they’re double-up care so you’ve got two carers with them, you know, all day.

Interviewer: Yeah, yeah. No, I understand. And I’ve gone to some houses that they had in-house carers that would change…

Respondent: They have the live-in carers.

Interviewer: Yeah, live-in carers, yeah, I’m not sure, live-in carers, and then they would change, I think, every two weeks or something. They had someone, yeah. Okay, so you’re also reviewing that, if it’s up to standard and then giving feedback on the concerns. Yeah, because in the beginning, yeah, now I understand. Okay, yeah. That makes more sense. I was thinking of the relatives, so that’s why. So, going back, so the manual handling training, you give it also to the relatives or to the carers from the agencies?

Respondent: No, so the manual handling for the agencies, they should have their own manual handling trainer. And so if I pick up any concerns, I will go to their managers and then they obviously have to make sure that they’re trained. I’m not allowed to give training to carers because I’m not a trainer, and so where we’ve got a family member, for example, that want to do… that want to hoist their relative, what we used to do is we used to have… [Organization name] used to have somebody and then they used to come out and then they used to provide the training for the family members to be able to hoist them. They’ve retired. We haven’t got anybody now, so I think in this instance, then we’re going to have to pay for a trainer to come in to train the family members if they want to do it. But with Huntington’s, if they’ve got double-up care then the family members don’t have to do the hoisting.

Interviewer: Yeah, the carers are trained. Okay. I understand. So, [name 1], you were saying earlier that you think if things were working well in terms of connection between different teams that people would see quicker actions, I guess.

Respondent: Yeah, they do, because some teams, they’ve got long, long waiting lists, so, for example, working with [name 2]’s team, this young lady with her chorea movements were so bad that everybody was involved, the consultants, they were trying to look for a placement so they could review her meds to see if that made a difference. You know, from start to finish from when they suggested it, it took three months. And at the end of the three months they decided it probably wasn’t a good idea. And yet, you know, if you’re going to review somebody’s meds then you need to do it now because…

[0:57:17]

Interviewer: When they need it, yeah.

Respondent: Yeah, they need it now, not in three months’ time, and that’s really the frustration really for when you need the specialist care.

Interviewer: Yeah, I understand. Yeah, the access needs to come, well, when it’s needed, not so further down the line. Okay. Alright. Any other differences that you want to highlight?

Respondent: Any other difficulties?

Interviewer: Differences that, you know, what sort of differences people would feel if there was a better connection between services.

Respondent: I think for the Huntington’s patients, I think if there was a helpline for them that they could ring and get help fast, you know, quickly, from a specialist team, like [name 2]’s team, I think that would be, yeah, I think that would be very, very helpful for the families, because the families need as much support as the patients, to be honest, because they’re going through an awful lot, aren’t they? They know they’re going to lose that relative, aren’t they? They know they’re not going to get any better, so they’re grieving and it’s a long process, isn’t it, for grieving. And I think sometimes there isn’t that services to support the families. You know, the focus is always on the patient, but yeah, I think the families could do with more support, some kind of helpline, some kind of services for them as well.

Interviewer: Do your families connect much with the Huntington’s Disease Association?

Respondent: I’m not sure they do. I’m not even sure that they’re aware about it, to be honest. I mean at [hospital], they’ve got obviously the neurology team, so there’s an OT there called [name 4] and I k now sometimes I say to [name 4], “Right, can we do a joint visit to go out and see this Huntington’s patient?” Her diary, there’s only her to do that, and her diary is so full up that sometimes it can be absolutely three or four, five weeks before she can fit them in, whereas if I see somebody and they’re having difficulties, I can usually go and see them in the same week.

Interviewer: Oh, wow. What a difference, yeah.

Respondent: Yeah. I do that. If there’s an issue, you know, give me a couple of days and I can usually squeeze them in somewhere, whereas with [name 4], yeah, it could be four or five weeks. So, if I need a joint visit with [name 4], sometimes I just go, do you know, I just go on my own and just go and see what I can do.

Interviewer: Yeah, because otherwise it just takes a long time.

Respondent: Yeah, it takes too long, yeah. You can’t leave people in that kind of situation.

Interviewer: Okay, so your impression is that people may not even be aware that the charity exists or they could…

Respondent: Yeah, exactly.

Interviewer: Because I think the charity has a helpline, that’s why I was thinking about it.

[1:00:29]

Respondent: Mmm, but I don’t know how good it is because I know, you know, this young lady that I’m talking about, every time there’s an issue, mum just rings me straight away, you know. Yeah.

Interviewer: Well, clearly, people tend to… then they ring… the more helpful people then get…

Respondent: Then they know that… yeah.

Interviewer: Yeah, they’ll check in with you all the time.

Respondent: Yeah, she does. I mean even if it’s like a medical issue to do with the meds, she’ll still ring me or…

Interviewer: Because she knows you’ll pass on, that you’ll signpost to…

Respondent: I will, yeah. Or I’ll make that referral or I’ll contact that person and say, “Look, I’ve chatted with mum and she’s told me A, B, C and D and what can you support with?” Yeah. And that’s why I keep my diary flexible really and that’s why I really enjoy my job, the fact that it is so flexible. I can squeeze people in, you know, either tomorrow or the day after. I can usually squeeze them in somewhere and go and sort them out. And I think that’s a good help for families because then they can see you’re reacting.

Interviewer: Yeah, yeah. As you say, that flexibility, but also to make it work as well, you know. Yeah, I don’t want to go back to the case workers, but I think there’s a lot to say with our conversation about professionalism and how to do your job right. Yeah, okay.

Respondent: And lots of new nurses, you know, I don’t know how long they’ve been qualified, they may never have come in contact with somebody with Huntington’s before. And all they’re concentrating on is those questions. Do they meet the criteria for our funding? And it’s always about it’s the funding, that seems to be the important thing. Are we going to fund their care or are we not going to fund their care? Whereas I always say to people, “I’m not even thinking about the money. I’m not even interested in the money, all I’m interested in, what is the issue and what can we do to fix it?”

Interviewer: Yeah, yeah. That’s the goal, as you were saying.

Respondent: Again, no.

Interviewer: Okay. [name 1], I’m going to do a couple of boring questions now, but I need to go through them to be able to characterise my sample.

Respondent: Okay.

[redacted]

Interviewer: Is there anything you’d like to add to our interview that we may have missed?

Respondent: Can’t think of anything.

Interviewer: Sort of like, “Ooh, I thought she was going to ask me whatever and she didn’t”.

Respondent: No, I think for me it’s the experience, that’s the most important thing, the experience for the patient and for their families really in terms of what we provide and how we provide it.

[redacted]

Respondent: No, that’s fine. Well, good luck with your research anyway.

Interviewer: Thank you so much.

Respondent: It’s important to get that lived-in experience.

[redacted]

[End of Transcript]