[0:00:00]

Interviewer: [redacted] Alright. [Name 1], so my first question just to start with a bit of a chat, and again, this is all anonymous and I am looking for your honesty throughout the interview, so we’ll start just, if you tell me a bit about your work. What is your role?

Respondent: So I’m a speech and language therapist, I’m a band 7 in the NHS and I just currently do community work, so we work in [location 1] generally, within the boundaries of sort of the [location 1] boundaries. I do a varied caseload, so I do sort of your progressive neuros as well as general frailty and sort of COPD and things. So obviously as a speech therapist, mainly dysphagia in communication, AAC, depending on what’s needed, a lot of MDT working. We’re really good in the [location 1], to be honest, we’ve got lots of good MDTs, lots of joint working with the physios and the OTs and things.

Interviewer: And these physios and the OTs are part of your hospital team? So when you say MDT, it’s really at your location or throughout?

Respondent: So I am employed by [location 2] University Trust, and we, but for [location 1] we sit out and we work out of the [location 3] Hospital. So my colleagues who do the outpatient and the community physio are [location 3] Hospital staff. So we’re sort of different Trusts, but in the same base, as it were, seeing the same patients. And then from a Huntington’s point of view, we link in with the team at the [location 4] Centre in [location 5] and Prof [name 2] and [name 3], who’s sort of the Huntington’s, the local Huntington’s advisor.

Interviewer: Yeah, so [name 1], with these two teams, so you’re employed by different Trusts, but is there, like, a shared medical record or a shared electronic system?

Respondent: No, wouldn’t it be nice?

Interviewer: You know, since you’re working together.

Respondent: So my colleagues at the [location 3] are still on paper notes. The [location 3] is bringing in electronic notes and electronic patient record, but you know, the wheels turn slowly. Plus in SWIFT, and our community staff use EMIS, which our GPs use as well, so we have a really nice bunch of stuff, and access to information. And then there’s obviously the Shared Care Agreements, so generally, amongst the MDT sometimes, we can sort of say, you know, “We know that you’re meant to have got this letter, but have you seen it?” and they don’t necessarily have it quite as quick as we do. So we can share in that sense.

Interviewer: Okay. When you say the Shared Care Agreements, is this something, like, official?

Respondent: Well, it’s just an on EMIS thing, I think, so it’s just that patients are happy to sort of have their data share across the community services, I think, so it means that, because it’s sort of speech therapy use it, dieticians use it, the hospice, [location 6] Hospice use it, and the palliative care teams, and the district nurses, as well as the GPs. So there’s quite a bunch of us that input onto it.

[00:04:16]

Interviewer: But this is to ask the patient permission for their records to be shared between providers? Or is there a care plan within it?

Respondent: No, it’s just a provider thing, I think, I’m not really sure how it works. It’s led by the GP, I think, so it’s sort of one of these, “We use these notes, and are you happy that the notes can be seen across the Trust and used by the professionals?” as it were. I’ve never really thought too much about it, to be honest, because it’s just so useful to have, I’m, like, “Well, I don’t want to know what the…”

Interviewer: Yeah, you don’t change what’s working well.

Respondent: Absolutely.

Interviewer: That’s the first time I’m hearing the term, that’s why I’m asking, I’m not familiar with it, but basically, it’s to say, to ask the patient and family who are they happy with looking at their medical notes?

Respondent: Yeah, yeah.

Interviewer: Okay, alright. So when you communicate with the team, with the paper-based team, is it, like, mainly phone calls, emails, like, between NHS.net emails and stuff like that?

Respondent: Generally they work in the office just down the corridor, so often we just pop along.

Interviewer: Okay, so you can physically, like, just get them round.

Respondent: Yeah, we can go down, yeah.

Interviewer: Okay. Is there anything, like, in place to be then more, like, regularly, or is it just as needed? Would you see/review a patient as an MDT?

Respondent: So from our point of view, we have a regular Parkinson’s and Parkinson’s Plus MDT that runs with the physios, the OTs, the dietician, the Parkinson’s Disease nurse specialist, and sort of speech therapy, on Teams, and that runs… The Plus runs twice a year, three times a year, and the Parkinson’s runs every eight weeks or something. And then the Huntington’s MDT we do twice a year, and that’s where we sort of flag up any patients that might be…we might be worried about or making any referrals that we might not have heard about and things, otherwise it’s just an ad hoc basis.

Interviewer: Okay. And I guess it’s, like, after those meetings, if something comes up, you go back to the [location 5] and go though, well, whatever questions you have?

Respondent: Yeah.

Interviewer: Okay. Do you have many patients with Huntington’s?

Respondent: Currently I’ve got seven open to me in the [location 1] area.

Interviewer: Okay. And they’re home-based, or are they, like, in nursing homes or other long-term care facilities?

Respondent: So I’ve gone one lady with juvenile Huntington’s, who’s in a sort of supported living-type place. I’ve got a few people at home with family, and I’ve got a few people in care homes.

[00:07:03]

Interviewer: Okay, so you go to the care homes as well, like…?

Respondent: Yeah.

Interviewer: Okay, so when you said you’re a community team, you go to people’s settings, or are they also coming to…?

Respondent: Sometimes they come in, sometimes they come in, it depends what we think is going to be appropriate, or if we can sort of get the space, as ever, room space is always a bit of a…

Interviewer: Oh yeah, I remember.

Respondent: A bit of a thing. But also, from a speech therapy point of view, I find that often you gather the best sort of data and the best relationship can be built when you’re going into someone’s home, often. Because you’re talking about eating and drinking, so it’s easy to see them with a meal at a mealtime, in their sort of home surroundings, or you’re talking about the communication and everything else, so sometimes it’s easier to be in that home environment, rather than in sort of a more clinical setting.

Interviewer: Yeah, true. And so if you get…so what would happen then, you get a referral from the GP or, you know, like, as an example, if you get a patient, how do you learn about a patient needing you?

Respondent: So we, essentially anyone can refer to us, GP, or consultant or physios or OTs. We also are lucky enough, I suppose, we’re an open referral, we have a self-referral system, so often if people have seen us before or otherwise, they can phone us, like, our office directly, and say, “I’m having problems.” Mostly the only people that do that are people who we’ve seen before, we don’t get that many sort of initial ones phone us directly. Generally it’s through, like, physio and OT or sort of GP sometimes, and neurology are often the ones. So they’ll write us a quick letter saying, “Oh, you know…” Often it’s just, “Please come and review this lovely lady’s swallow,” and that’s it generally.

Interviewer: Yeah. You don’t get the rest of the story, yeah.

Respondent: Yeah.

Interviewer: And then you go see them, like, you arrange your own appointment to see them?

Respondent: Yeah, so if the letter’s enough, we can triage just from the letter, and put them on our waiting list. If it’s not, we’ll phone and see if we can fish out a bit more information about what might be going on and what the difficulties are. Then they go on the waiting list and we run a waiting list, and probably within eight weeks, usually, we get to see everyone, so it’s not horrendously long. When we’re really, well, when the staffing’s really nice and we’re on top of things, it can be sort of four to six weeks, but at the minute, it’s probably more like 8-12. So then it’s a case of phoning and arranging to go out and see them.

Interviewer: Then is there, like, how often would you, I mean, I guess it depends case by case, but how much does it vary?

Respondent: So, well, it depends what we’re doing. With sort of the juvenile lady with Huntington’s that I’ve seen today, I saw her for the first time in November, and we sort of said everything was stable enough, it was all okay, so we sort of, at that point we discharged her and said, “Please come back to us.” So things have deteriorated a little bit, she was a bit poorly in January and things have gone off. So her mum has phoned to say, “Oh, please can you come back out?” So I’ve gone back out today, it’s saliva management and maybe a bit of reflux, so what I’m going to do is write to the GP, I’m going to send out some logs for her, a and then in another probably 8-10 weeks, I’ll phone mum and sort of arrange to go back out and see, and then from there, I can see again. If I’m doing some more therapy, with sort of, like, a Parkinson’s patient, we do a block of therapy that can be, like, four sessions a week for four weeks, so it really does vary. We don’t keep a lot of people on, like, an open review or a review that we sort of check in. Some of MND patients, we tend to keep open because they change so rapidly, so we tend to review them every couple of months. And some of the Huntington’s patients we’ll keep open, if they’re sort of not very stable, but, like, your Parkinson’s patients, or your PSP and things, generally what we’ll do is say, “Things are as good as they can be for the moment, we’ll discharge you, but please come back to us,” because we found that it works better and people will actually be more proactive in getting back in touch with us if there’s a problem. If you keep people on sort of really open reviews, it tended to be that people would just sit and wait to hear from you, and then you’d phone and they’d say, “Oh, we’ve been having problems for, like, three months.” And you’re, like, “Oh, why have you not phoned?” It’s, like, “Oh, because we knew you were coming.”

[00:11:49]

Interviewer: Eventually, yeah.

Respondent: Yeah. So we find that by sort of discharging and encouraging them to come back, actually, it works a bit better for everyone.

Interviewer: Do you…when you go in and you make an assessment and the plan, and I guess, is there, like, much teaching with a carer, for example?

Respondent: Yeah, yeah, we do a lot of, like, programme training in care homes, particularly, and especially around dysphagia, we do a sort of more generic training package. And out in the community and things, we’ll get carers or we’ll get family, or, you know, whoever’s most involved, and it can be a bit more bespoke, depending on what’s going on.

Interviewer: Is there anything you think is different, you know, from treating these issue with Huntington’s patients, compared to a Parkinson’s patient, for example?

Respondent: Generally I find the Huntington’s patients can be a lot more variable and things, they…if they’re poorly, things really knock off. Parkinson’s is obviously a more general decline, it’s a slower decline. Generally Parkinson’s patients, from my point of view, if you go out because they’ve mentioned their swallowing is a bit worse, you’ll go out and they’ll say, “Oh, well, I found that I wasn’t managing bread so well, so I changed it.” And they tend to notice that and recognise that and change it themselves, whereas the Huntington’s patients cognitively can be quite a lot more impaired and don’t recognise it so well. So you have to do a lot more work with families, sometimes mood and sort of…we’ve had a couple of people who’ve been quite aggressive with things, and sort of… Again, it’s from my experience, so it’s probably not a wide thing.

Interviewer: Sounds right, yeah.

Respondent: Some of our Huntington’s patients have had sort of substance abuse problems and things, and that’s probably where I’ve seen it more than with, like, other populations almost.

Interviewer: Substance abuse? Alright.

Respondent: Yeah, not everyone, but sort of definitely we’ve had a few that are sort of more heavy drinkers, or a couple of sort of, yeah, drug users.

Interviewer: Okay. And when you train the relatives, do you feel like a difference, does it improve? Or are they able to follow?

Respondent: Oh, it’s hit and miss. I think that’s, you know, the same everywhere. I think…I love working where I work in [location 1] but I think probably we have quite a big population of people who probably weren’t schooled to the highest, you know, we have a lot of people who worked down the pit when the mines were open and things, so generally, I would say sort of the level of education is not quite so high and things like that. They’re not the people who phone the doctor if anything’s wrong, they’re the people that just sort of sit and make do.

[00:15:05]

Interviewer: Yeah.

Respondent: So it can be difficult, you’ve got to sort of try and build that relationship first before you can go in and make changes, because otherwise people will be a bit, like, “Oh, we don’t really see what I’m doing.”

Interviewer: Yeah, I guess that’s why as well you have the self-referral, but only people that already know of you will contact you.

Respondent: Yes.

Interviewer: Instead of someone going on the web and going, like, “Speech and language therapy, [location 1],” and then you popping up.

Respondent: Yeah, absolutely.

Interviewer: That doesn’t really happen.

Respondent: No, not so much.

Interviewer: Okay, so what’s the, like, the feedback you get from your patients with Huntington’s, regarding, like, you know, they’re happy with how things are working, or they complain about certain things, or how does it go?

Respondent: No I mean, from a speech therapy point of view, everyone’s always seemed pretty happy, they seem, you know, quite pleased with how efficient we are and how quickly we can turn up. I think they like the fact that we check in with sort of, like, the [location 5] team as well, because obviously they’re seeing them every sort of six months or something, but I think… Yeah, I think they feel positive that we know of the specialist team, so it’s not just like we’re coming out completely unaware. Again, with Huntington’s, often they know us already because we’ve seen family members, you know, one of my colleagues had seen sort of dad and…grandad and dad, and then the daughter, sort of thing.

Interviewer: You go through the generations.

Respondent: You go through the generations, so you know, they’re generally, they already know us, and they’re already sort of aware of who we are.

Interviewer: I see. With the nursing homes, or you know, long-term care, because I mean, I’m getting a lot that the staff rotates a lot, so even if they’re trained, it dissolves because people move.

Respondent: Yeah.

Interviewer: Is that your experience as well in [location 1]?

Respondent: Yeah. It’s that rolling training package to capture as best we can, and you know, some of it is hoping that patients end up in certain homes over others, because you know that certain homes are going to be better equipped, but you don’t, you know, you don’t get a say on that. But I think a couple of our homes, in fairness, have been pretty steady, the staff have been pretty steady. But I think it’s the same everywhere, I think, yeah, you know, people move on or you train people up and then they go on mat leave and things. So yeah, it’s the nature of the care sector, I think.

Interviewer: Yeah. But I mean, would you go, sort of like, you go to a home and you can see, “Well, this isn’t…” Or the carer will say, you know, “The social worker’s been around, and actually, we’re thinking it’s maybe time to move him out of the house into care.” So would you ask, “Okay, so which care setting is he going to?” and then go see them there? Or is it that the care home gets a patient and they’re, like, “Oh, he keeps on choking, let’s see who can come to us?”

[00:18:37]

Respondent: It depends, again, if they’re moving from, like, a home address in [location 1] to a care home in [location 1], if it’s the [location 1] partnership, they will still be under me, so if they’re still open to me, I’ll follow them through, I’ll phone the care home and say, you know, “They are know to me, these are the recommendations, this is sort of how best to support, please contact us.” If we don’t know, or they’re discharged, often it comes back from, like, the care home, they’ll phone, or they’ll phone the GP and say, “Oh, they’re really struggling, can you do something about it?” Generally, I would say, again, the care homes are quite well versed as to who we are, so they generally know who to contact, on the whole, not all of them. They will phone us before they do anything drastic like start everyone on thickener and puree.

Interviewer: Okay. And are you the only speech and language therapist at your team, or are there more?

Respondent: So for [location 1], it is me, my colleague is part time, but she also does management, so her clinical hours are quite short. And then we’ve recently had a band 5 join us, but she’s not sort of seeing the complex cases yet, and she’s not dysphagia trained yet. So currently, it’s pretty much me, but there are other bodies, we’re just waiting to…

Interviewer: To get them up and running, yeah.

Respondent: Absolutely.

Interviewer: Yeah, okay. And did you need any more, like, Huntington’s Disease-specific training, or it’s just dysphagia like in any other neuro condition?

Respondent: Oh, that’s a hard question. I’ve been doing this for sort of [10-15] years, so it’s what you pick up along the way, I suppose. I started in community and stroke rehab, so I’ve always done community, and then I sort of…the places I’ve worked have always been a mixed neuro and sort of medical caseload, so I’ve just picked it up along the way and seen people, and you know, done webinars and things when they’ve come up and things. And then you just start getting a feel for it. So often, with your Huntington’s from a speech therapy point of view, it’s not necessarily a dysphagia point of view, in the sense of it’s going down the wrong way and we’re concerned about aspiration, it’s a pacing and choking risk, generally. So often it’s about behaviours, it’s about mealtime support, it’s about family support, and if we can do all of those things before modifying diets, because often it’s that sort of external factors, rather than airway protection factors.

Interviewer: Yeah, and their cognition.

Respondent: And their cognition, yeah, so it’s…they are a population that we don’t necessarily sort of expect the newly qualified to see, because it can be quite scary to go in on that first time you see someone and you’re, like, “Oh, you’re really just chucking that bread roll in there,” or, “Then you’re sort of having loads of peanuts,” type of thing. And then you’re trying to have that discussion about, “Oh, should we maybe cut that up a bit?” and you know, it doesn’t necessarily go very smoothly.

Interviewer: Yeah, it doesn’t really sink in many times.

Respondent: No.

Interviewer: Okay. So is there any particular, like, specific teams you work with?

[00:22:15]

Respondent: In what sense?

Interviewer: For, you know, to do, like, these care plans with Huntington’s Disease patients, you’ve mentioned your colleagues down the corridor.

Respondent: Yeah, so it’s sort of us generally, one of my dietetic colleagues does the…[name 4] does the Huntington’s, so I go out jointly with her quite a lot, we see a few of ours jointly quite a lot.

Interviewer: Okay.

Respondent: Again, it works well for us because we get a good picture on it, it works well for the patients because they’re then not having to book in loads of professionals.

Interviewer: On different days, yeah.

Respondent: And then we have, like I say, the MDT sort of twice a year, and that’s…today we had it, and it was [name 3] from the Huntington’s Association, it was [name 5] who’s the dietician at the [location 5] and [name 6], who’s a speech therapist. Sometimes we have [name 7] as well, so it tends to be more sort of AHP-based.

Interviewer: Okay, the neuropsychiatrist, Dr [name 2], he doesn’t usually join for these?

Respondent: He’s, yeah, we don’t manage to get hold of him, but obviously the team are quite, you know, they work quite closely, so they can flag it up via them almost, and it works well enough.

Interviewer: Is there any neurologist in these communications?

Respondent: So again, it varies. A lot of our patients are just under Prof [name 2], so they will be seen in [location 5], they will go to [location 5]. Some of them will be seen in [location 6] by sort of Dr [name 8] or Dr [name 9], and again, they’re quite accessible, I know them quite well from just a general work point of view, so they’re quite accessible if you need them on email or sort of letters and things. But I think most of our Huntington’s patients are seen purely by the [location 5] team.

Interviewer: So I thought it was [name 10] doing the HD advisor for [location 1]?

Respondent: [Name 3] is the lady that we’ve linked with for a number of years.

Interviewer: Okay.

Respondent: I don’t know how they’re all split up, I don’t know if she covers just, like, the [location 8] bit of it.

Interviewer: But you’ve met [name 10]?

Respondent: No, I don’t know the name.

Interviewer: Oh, you don’t know, never mind then. Okay, yeah, I’m asking because I went to him to find, to try and find patients.

Respondent: No, [name 3] is the lady that we link with and who sort of has a good handle on all of our area patients.

Interviewer: Okay. So [name 1], you’ve mentioned you have a band 5 starting, or started, and of course, well, you’re building her up.

Respondent: Yeah.

[00:25:09]

Interviewer: So how does it work when you, like, hand over patients, when the time comes, and I’m sure you’ve done this many times, because I’ve worked in the NHS and I mean, inductions were, like, our bread and butter, how will she pick up on, like, the people to contact, you know, like the ropes?

Respondent: The team. We do a lot of joint working, so she’ll do the sort of generic…the generic stuff, she’ll get on her feet with sort of the easier, you know, your sort of dementias, your sort of strokes, those sort of things, that you’re more…you learn more about in uni, almost, and then we’ll start doing sort of more joint working for the more complex prog neuros. And then as that happens, then she’ll be involved in, like, the MDTs and then we’ll be more aware of who the team are around you and things.

Interviewer: Learning on the job, it’s not like there is a…you know, an algorithm or a protocol or a pathway, or that she would know, like…

Respondent: No, no, it’s a learn on the job.

Interviewer: On the job, okay. Good. Do you refer many patients, like, to the Huntington’s Association, to [name 3], like, when there’s certain difficulties or…

Respondent: Generally, I would say by the time we see them, they already are known to the Huntington’s Disease Association, on the whole. If they’ve been offered it before and declined, then you know, I always offer it again and I will always sort of see f I can refer. I’ve got a gentleman in the next couple of weeks that I’m going to review, who’s sort of declined it before, but actually, things have changed a bit, so me and the dietician are going to go out and say, “Oh, would you like [name 3] to sort of get in touch, would you like the Huntington’s Disease Association involved again?” But yeah, generally, because of where we come in the pathway, as it were, we’re sort of often mid to late stages, so they’re often already quite well known to a lot of the supportive team, and, like, the HDA.

Interviewer: Do you link with palliative care, I mean, is there a palliative care team there, or…?

Respondent: So our palliative care unfortunately is a bit stretched on the ground, so they will take on the complex symptom management patients, but apart from that, they don’t really have capacity to sort of see anyone. So often it’s sort of going back to the GP. There’s a consultant that you can sort of...that I know and I can email, but again, she’s really busy, so it can be really difficult to sort of get hold of her. But yeah, for your more standard palliative care stuff, it’s a bit h it and miss from that team. We have [location 6] Hospice, which is a day hospice based out of the [location 3] site, and they run quite a few things, and so sometimes they’ll have people that can get in touch or our patients can go into the day centre and things and do their courses.

Interviewer: So for stuff like NG tubes or PEGS, I’m asking about this because you’re quite…

Respondent: Yeah, so NG tubes, we don’t generally support in the community in [location 1], we don’t have sort of the…the carers don’t support those, and yeah, I don’t think I’ve seen any at all in the last at least five years. PEGS, it will be sort of led by dietician often, and then referring either to sort of, like, your HCW or the [location 3] for assessment under gastro and things. Again, PEGS can be a bit problematic because if you can’t manage it yourself or if you haven’t got family who will manage it, it can be really difficult to find carers who will manage it. So it means that sometimes if you have a PEG, it means that you have to go into nursing care, because of that, unless you can get funded sort of 24 hour care and support. So it’s not as smooth as you’d like.

Interviewer: And yeah, okay, do you speak to private carers, like, sort of like if there is CHC in place, do you educate them as well in people’s homes, like, the private carers?

Respondent: Yeah.

[00:29:56]

Interviewer: Or are the agencies…

Respondent: It’s all the same really, we’ll just see the carers, whoever they are and wherever they’ve come from.

Interviewer: Whoever’s there.

Respondent: Yeah, whoever’s there, absolutely. And then wherever the money comes from, they deal with.

Interviewer: Okay. Do you ever have any involvement with social care workers or…?

Respondent: Sometimes, not often. Again, I think since Covid, social care has bene a real problem, they’ve bene a nightmare to get hold of, everyone seems to work from home, so no-one ever answers the phone. I think even today, they were talking, you know, people have been trying to get hold of a social worker for one of their HD patients and just…she’s just not got back to anyone, and she’s really difficult to contact. So social care is a…yeah, tricky, that’s probably one of the trickiest parts of it, to try and get everything pulled together, especially from a care and funding point of view. The health side of things works quite nicely, and then the social care side of things not so much.

Interviewer: Yeah. YOu know why I’m asking, I mean, my project is about integrated care, so…

Respondent: Absolutely.

Interviewer: And this is not new to me.

Respondent: No, yeah, there doesn’t seem to be a system for, like, certain social workers for certain conditions, you know, it really does seem pot luck of whose desk you end up on. So it’s not like we can even say, “Oh, please come to the meeting,” because there could be six or seven or more sort of known social workers.

Interviewer: Yeah, how do you even know who to contact, you know, like, how do you even start?

Respondent: YOu start by asking around and seeing if any of your other colleagues know of anyone. Sometimes if things have deteriorated and people are panicking, then the social workers tend to contact us, so then you’ll have a name. But then apart from that, often, it’s phoning their switchboard and saying, “Can you check your records, is this person open?” But then, you know, again, they’re very…their sort of data protection and things is very shirty and it’s not…they’re a bit insulated, so even when you phone up and say, “I’m from the NHS, I’ve got their NHS number, I’ve got all these details, can you at least tell me if they’re open or not,” it’s always a bit, like, “Oh well, we’re not really sure, we’re not really sure, and the person who you might want to speak to is not in until, like, next Wednesday.” So it can be tricky.

Interviewer: When you do manage to speak to someone, for a patient, is it that same person picking up the case throughout?

Respondent: Yes. Generally. And the people I’ve dealt with who’ve had social workers, it has been the same person.

Interviewer: Okay, that’s good.

Respondent: Yeah.

Interviewer: I guess once you find out who it is, it’s easier then.

Respondent: Yeah, as long as I’ve got their contact, yeah, absolutely, it’s easy.

[00:33:06]

Interviewer: Okay. It is what it is.

Respondent: Yeah, absolutely.

Interviewer: What would help in this case? You know…

Respondent: I mean, in an ideal world, it would just be really nice to have more access to the social workers, it would be nice to sort of know where they’re based, or to have some sort of contact to make it easier from that point of view. In an absolutely ideal world, it would be nice if you had someone, a particular person or a particular two people who took on the sort of the Huntington’s cases, or, like, the Parkinson’s cases. It would be nice to have someone who was an expert in that area, who you could then invite to the MDTs and things. Because then you’d know that if a Huntington’s patient ended up on your desk, you’d know who you could contact, and you’d know who sort of would be the point of contact.

Interviewer: Do you have these…you know, not being clear about who to contact with motor neurone disease patients as well?

Respondent: From a social worker point of view, absolutely.

Interviewer: So it’s the same across.

Respondent: It’s the same across, yeah.

Interviewer: Okay. Because it’s not a disease problem, it’s a system problem.

Respondent: No, it’s a system problem. It’s, yeah, it’s not a disease problem at all, it’s the system. I assume it’s a complete lack of staffing problem and things as well, I assume that they’ve got a lot of people open and not a lot of staff or anything. And I think, you know, their problem often is if they seem someone to have enough, like, money and things, then they pull out, and then it’s a bit, like, “Well, you’re on your own now,” whereas if they need funding, you almost get more support, but if you’re self-funding, they’re not necessarily, they’ll be, like, “Oh well, here’s a leaflet,” but you don’t necessarily get a physical person to support.

Interviewer: Are there other professionals that are hard to get hold of, I mean, in your experience?

Respondent: I mean, any sort of psychology or psychiatry, anything to do with sort of mental health is very problematic in our area, there’s just not really anyone around. It’s really difficult to get, which is why we refer some of ours back to the [location 5], in the hope that that team is slightly better outfitted with it, but I think even their side of things, it can be a bit of a problem.

Interviewer: Yeah.

Respondent: But yeah, sort of neuropsych or psychology or anything is really problematic to access.

Interviewer: Is there a community mental health team in [location 1], or not really?

Respondent: Yes, but you sort of… you have your IAPT, which is your general talking therapy that you can self-refer to. There is a community mental health team, but how helpful they are is another question entirely, I think, and what they will actually do, you know, they’re okay with your dementias, but if you sort of chuck in anything that’s a bit more complicated than often your run of the mill dementias, it’s a bit tricky, even if you’re trying to get someone to see what I think is a PPA, as opposed to an Alzheimer’s, it’s a bit tricky.

Interviewer: And why is that? Because they just don’t have the knowledge or…?

[00:36:48]

Respondent: I have no idea. I don’ know if it’s just a system thing or a numbers thing, or a…yeah, or they’ve not come across it so much. I really don’t know. But it’s just difficult to access them for anything more complicated than your sort of your regular dementias or your frontotemporal dementias, I find.

Interviewer: What answer do you get if you, you know, you or the patient, whichever, I’m not sure, or if their GP makes a referral and the community mental health team comes to see them?

Respondent: Often you get a lot of declined referrals, or, “We don’t think this is in our area,” or you know, “Not appropriate for the service.” I can’t think of anyone recently who’s been seen, so I can’t think of anything, how it happened after, to be honest. I think…

Interviewer: But basically they say, “It’s not within our remit”?

Respondent: Often, yeah.

Interviewer: Okay.

Respondent: Yeah, “Please go back to someone more specialist,” and you’re a bit, like, “If there is anyone more specialist, please let me know, because we’re in a bit of a cycle now.”

Interviewer: And in this situation, it’s because people are aggressive or you know, there’s obsessive behaviours.

Respondent: Yeah. And it’s usually linked to the conditions, it’s things more linked to sort of that neurological progressive condition, as opposed to that sort of…yeah.

Interviewer: Okay. So what would make your work easier, if anything, apart…so you’ve mentioned social workers, or, you know, if everything else is working fine, then…

Respondent: I think we are really lucky, I think it does work quite nicely, I think we have got quite a nice MDT. I know that even on the call today, the team at the [location 5] were saying they’re really grateful that they’ve got the network of us, because we can keep an eye on people more routinely and things, so they know that they can refer to us and that care will still go on. So I think actually, I’m quite privileged to be in an area where it works quite nicely within the bounds of sort of the NHS and what you can provide. We are lucky that I’ve got a team around me that, you know, I know that if I say, “Oh, this isn’t quite right, can you go back out,” the physios will do that for me, and if I say, “Oh, shall we go and see this person jointly,” we can arrange that and things. So actually, on the whole, I feel really, I do feel privileged that it works quite nicely.

Interviewer: Yeah, I mean, it does sound like, you know, like there’s already an established network around your county.

Respondent: Absolutely, yeah.

Interviewer: [Name 1], when you go and see these patients, and it sounds like you do some visits by yourself, how do you assess the risk of you going by yourself? Or if any, in any way.

Respondent: It’s a bit suck it and see sometimes. Obviously the system really helps because if the GP records or if the district nurses records, there are alerts and things, but if it’s completely unknown, it isa bit sort of, “You’re going to have to suck it and see,” and you’ve got the risk policy and the lone worker policy, and use it if needed. I think generally, I’ve never had to, I’ve never been in a situation where someone’s been so aggressive or anything that it’s been a problem, or you know, been problematic. If it’s someone where we’re looking and we think, “Oh, it really isn’t looking great,” then we’ll arrange to go out as a joint.

Interviewer: A joint visit.

[00:40:53]

Respondent: Yeah. And again, that might mean that someone has to wait a bit longer, but if it’s someone who’s really looking a bit red flag or something like that, then we’d arrange to go out as a pair.

Interviewer: Would you have, like, a little red sign on their records, like, “They’re allergic to penicillin,” but aggressive, sort of?

Respondent: So they have, like, a drop down bar and you can have alerts on that, and often it will say sort of, “Visit in pairs,” or it will indicate that there's something else that you have to look at on documents and things to flag it up.

Interviewer: Do you have many patients without…that live by themselves, like, without a relative, a spouse, or a daughter?

Respondent: In the general caseload, yes, and then we have got a few people with key safes and things like that, and you’d let yourself in. I think of the Huntington’s caseload, no, I think everyone’s got a spouse or a family member or someone that we sort of arrange, we can arrange visits through and things, and arrange to be there.

Interviewer: Okay. So [name 1], what’s the difference you’re trying to make on their lives, like, if you could measure your success, your impact, what would you look at?

Respondent: We are, or I like…in the quality of life way, it’s a, you know, “Can I support you to eat what you want for as long as we possibly can? Can we look at things, can we keep you going without sort of artificial nutrition and things, if that’s what you want, for as long as we can, can we do it without risk?” Or if we’re looking at risk, is it actually that much of a risk? You know, is the difference between thin fluids and level two thicker fluids really that significant from an eating and drinking point of view. And then I suppose, from a communication point of view, it’s, again, it’s quality of life, it’s, “Can you still communicate with the people that you want to? Can you still say as much, you know, the things that you want to say?” It’s a, yeah, quality of life, it’s a reducing frustration, I think is probably the biggest thing for me.

Interviewer: If you had, I mean, do you think they get seen often enough? Again, you have limited resources, so it’s not criticising how often you see them…

Respondent: No, no, absolutely.

Interviewer: But I mean, like, again, in an ideal world…

Respondent: In an ideal world, it would be nice to be able to see them more, especially from sort of a communication point of view, it would be really nice to be able to do more training or to be out there more or to do more that is really bespoke and tailored to that person, rather than having to use sort of generic resources and things. It would be nice to be able to sort of say, “Oh, let’s have access to lots of, like, iPad AAC,” or other sorts of AAC that we can try, that would make a difference, rather than saying, “This is all I’ve got to offer.” I think from a swallowing point of view, I feel that actually, it’s managed quite nicely, generally, you know, you see people as and when and sort of routinely through the year, but I think that’s managed well enough. But I think, yeah, in an ideal world, it would be nice to be able to offer more communication input.

Interviewer: Yeah, I’m asking because I spoke to someone recently and I’m saying this because it was outside your county, you wouldn’t know this person – and they were, like, “Do you want milk…” was it…it was a fag or milk, like, just because they said the words, like, because the person had impairments with their speech, it just sounded like the same. So they were showing stuff so they pointed, and I asked them, “Well, you don’t have other, like, what’s the way of communicating then?” and they were, like, “Well, there’s just not enough, like… They left the board, but he just doesn’t use it.” So I’m always thinking, you know, if there was more time to practise and even before it gets more advanced. But you know, many patients will save their, you know, bank their voice, when they have a voice, they will go, “Like, right…” So it’s like these early planning, but you’re quite thinly spread.

[00:46:07]

Respondent: It is, it is. And I think with the HD patients, the cognition is another layer on top of that, because you try things, but to…I’ve got a really nice lady, and she’s recently gone into a care home and her voice bothers her, and it bothers her that people don’t always understand what she’s saying, but with the resources I’ve got, she doesn’t really want to try what I’m offering to her. I’ve done, like, communication books, I’ve done training and things, but actually, she wants to talk. And unfortunately, it’s trying to support people to understand that actually, it’s a declining thing, it’s not a, “We can make it better,” it’s not even if we did therapy we could make it better, because it’s not. And then, well, someone took, one of my colleagues took the light writer out, and I don’t know if you’ve seen or know what they are, but they… It’s an AAC device, and they’re really expensive for what they are, but essentially, it looks like a little tiny typewriter.

Interviewer: Oh right. Oh, that’s going to do well…

Respondent: Yeah, with a little bar across the top that you sort of have to type in, and then it will either scroll across or it will talk, and I specifically said, “Can we not try an iPad with this lady, because she uses an iPhone, and she does text her daughter, but the dyskinesia is problematic, the create movements are problematic, so she can’t sort of…”

Interviewer: She didn’t have the fine…the control on the fine movement.

Respondent: Absolutely. So I was, like, “Can we not try an iPad, because she’s familiar with the technology, and it’s just a bit more neutral.” And also, from my point of view, we can switch from text to then picture-based symbols and things, as it progresses.

Interviewer: Yeah.

Respondent: You can get lots of nice grids that go over the top that use it the same as a keyboard. So I have twisted my colleague’s arm and said, “Can we not try again?” Because in our team, we’ve got sort of a…what we call an AAC specialist, who has access to sort of those AAC things.

Interviewer: That’s great in the right…

Respondent: It’s great in the right thing, but it can be a bit hit and miss, and when you initially sort of emailed and said, I was saying, “Oh, can we not look at this?” They sort of said, “Oh, we don’t really like iPads because Huntington’s deteriorate so quickly,” and I’m, like, yeah, that was my face as well! I was, like, “This lady has had Huntington’s for, like, 20 years or so, and she’s only just recently started to have a bit of a problem, and it’s still pretty stable.” And, like, generally, they don’t fall off a cliff, generally it’s sort of a…

Interviewer: Yeah, well, it’s not known by being a quick progression condition like MND, yeah.

Respondent: Exactly. So when you’re emailing one of your team who’s meant to be a specialist in this rea, and that’s the first response you get, it just makes me go a bit, “Argh, I’ll just do it myself, but I haven’t got the technology here, I need you to come out because you’re the ones that have got the keys to that cupboard.”

Interviewer: And they thought it was, like, a waste of technology on the…this person?

Respondent: Yeah, almost, yeah. They don’t think they’re going to use it, they don’t think it’s, you know, they think it will change too quickly. But that’s the point of an iPad because there’s so many lovely apps, you can go from, you know, text apps to picture apps to…

[00:49:44]

Interviewer: Gifs, just get her to pick…yeah.

Respondent: Absolutely.

Interviewer: That just shows the lack of experience.

Respondent: The speech therapy world is not quite caught up in the technology. So AAC is obviously a big thing and everyone loves Stephen Hawking and the eye gaze and stuff, and then when you try and explain eye gaze, it’s not that quick and it’s not that helpful and it does not work for everyone, that is problematic. But generally, speech therapists are often a bit, like, “Oh well, you know, not everyone can use high tech AAC, and you need to have paper-based backups.” But my argument is, in this day and age, how many people won’t let their phone charge down to no per cent? It’s not, you know, how many of our 80 or 90 year olds still don’t understand how to use a phone? And actually, it’s minimal, like, more and more people on our caseload will have, will be technology fluent and will have children and grandchildren who are technology fluent and they are, you know, of an era where everyone’s using email and phones. So I think it’s trying to get that through to speech therapy that actually…

Interviewer: If you give them a phone book, they probably will stare at it, “What am I supposed to do with this?”

Respondent: Yeah, absolutely, “What do you want me to look at this paper?” So it’s trying to get speech therapy to understand that we’ve moved on, and actually, we don’t need to necessarily be so worried about the technology, and we do want to try and sort of… YOu know, if I can buy an iPad with an app on it for, like, £500, or a light writer for, like, £3500, what is actually a better use of everyone’s time.

Interviewer: And the money, yeh, the funds, I mean, we’re always so stretched.

Respondent: Absolutely. So yeah, so there’s an internal training bung as well, I would say.

Interviewer: But this is, like, it’s a professional culture, sort of, like, behavioural thing, it’s not just…one individual?

Respondent: No.

Interviewer: It’s just moving the field with the times.

Respondent: It’s within the field, and speech therapy is, you know, I always call us sort of the paupers, in to, like, physio and OT. We don’t get the funds in the same way, we don’t, you know, the research is not there, people are not always research-minded, so we do a lot of stuff in speech therapy because historically everyone’s done it and it’s worked okay. We don’t necessarily do it because there’s a really good evidence base for stuff. And that is changing, it is slowly changing, especially over, like, the last five years or so, it is improving, but it’s a slow, you know, we were the twinset and pearls profession, that’s what they called us.

Interviewer: You are what?

Respondent: Twinset and pearls. So the historic view of a speech therapist was the sort of tweed skirt and jacket and the string of pearls, sort of white, middle class woman.

Interviewer: I’m very disappointed, [name 1], you really haven’t dressed to the occasion!

Respondent: Exactly, in my polo shirt… So I think, you know, it’s changing that profession, it’s changing how that profession looks, it’s changing the sort of diversity and the intake and things like that. So speech therapy is slowly, slowly coming round, but it’s, you know, it is slow.

[00:53:10]

Interviewer: Yeah, I remember doing, I mean, I think throughout my whole career as a research sister, I saw one study with, I think was it Lee Silverman Technique.

Respondent: Yeah, we still use it.

Interviewer: And it was a study on Parkinson’s and that. And yeah, it was very hard to get anyone to even consider, it wasn’t my…the Parkinson’s part I was fine with, but yeah, I remember having many conversations with the SALT department, to see who, if anyone, would like to take on the charge of… But yeah, it was the only study, so as you’re saying, you know, there aren’t many, it’s not that common to see research in speech and language therapy. Which does affect, you know, improvement and evidence-based care.

Respondent: Absolutely.

Interviewer: Okay, so [name 1], I got from your…well, one of the things I got from our conversation today in terms of co-ordination and looking at integrated care, is that there is improvement on social services, not that I’m saying it’s…a problem, like, individually with anyone, but basically that the link between health and social is being really hard to make, and actually, you can spend a long time, and time is money, and we don’t have that much money in the NHS. You spend a long time just trying to find who is the right person to speak to. Once you get hold of the person, then it becomes easier, but actually, who to link with, it’s hard.

Respondent: Yeah.

Interviewer: While with other colleagues, they may even be from a different institution, but you already have those connections established, so it’s, you know, why not make the same with social services basically.

Respondent: Yeah.

Interviewer: So lets’ just, you know, take some…I’ve got a couple of boring questions, because I told you an hour. How old are you, [name 1]?

[redacted]

[End of Transcript]