[0:00:00]

Interviewer: Good. Alright, so can we start if you tell me a bit about your role?

Respondent: Okay. So, I’ve kind of got two roles. So, I’m Co-Director of [Location 1] as a company but also my in-house role is Quality Assurance Manager. So, I kind of have an overview of all the different departments. My background is in care and learning disabilities and things like that, so I have a particular interest in the care side but audit and just very much make sure everyone is being the best they can be.

Interviewer: Okay, yeah. So, what you are saying is that you don’t give direct care but basically you have that oversight to raise the standard of care or to keep it at a certain level?

Respondent: Yes. I mean we are multi-skilled so I can and do provide care when I need to; I’m able to. But I am much more involved in the admissions, the care plans, the documentation and making sure everything is at it should be. But we’re all multi-skilled here so we are all trained to provide care.

Interviewer: Yes, of course; yeah, okay. And how big is [Location 1]?

Respondent: So, we have 30 beds.

Interviewer: Okay.

Respondent: And we have a multitude of different complex needs.

Interviewer: Okay. And do you have patients with Huntington’s at the moment?

Respondent: Yes, we do. We are almost one third Huntington’s. We have, by the end of the week, 10 residents with Huntington’s Disease.

Interviewer: Okay, alright. And what training do staff have, if any, to manage patients with Huntington’s?

Respondent: Most of it comes from the experience of being here. We have a connection with the Specialist Nurse Advisor from [Place 1] who is incredibly supportive to us, and she does training with all of our new staff, she does troubleshooting sessions. We, as management, often meet up and she gives us advice over individuals. And we’re also now getting more training with positive behaviour management and things related to Huntington’s but that also could be related to other things. But most of our, we’re told, our best training, our best knowledge, has come from caring for these residents for many years now.

Interviewer: Okay. Do you know how that started? I’m asking because it can happen that patients are refused in institutions.

Respondent: Yes. So, my parents originally managed this care home and they had cared for residents with Huntington’s within the most institutionalised hospitals in the past and were happy or confident to care for people with Huntington’s, and I think that then grew and they passed on their knowledge. And we as a care home have always welcomed complexity and have liked a challenge and were not willing to refuse people based on that, so we’ve raised our level in order to accommodate their needs.

[0:04:15]

Interviewer: And when you say you’ve raised your level does that mean as well in terms of numbers that you’ve had to?

Respondent: Yes, which doesn’t always go down well with people saying, “Why do you want to charge this?” or, “Why do you need three people to one?” and things like that. But, yes, we have 10 staff on in the daytime for 30 residents and we have 5 at night now waking. So, we can provide that high level of care and also that high ratio because some people, particularly with Huntington’s, can need two or maybe even three people at a time in order to manage their needs.

Interviewer: Okay. Do you provide any therapies or what sort of stuff do you have at the care home?

Respondent: Yeah. So, we have care staff but we also have Activities Coordinators and we have Chefs, we have maintenance, we have non-care staff as well, housekeeping teams, in order to provide that personalised care because for some people they might really need to be out a lot, for some people it’s going to be more the Physio and the OT-based stuff, some residents will thrive on sensory type interaction. And so due to the diversity of the needs we find we need staff doing many different things.

Interviewer: Right. So, you have in-house Therapists?

Respondent: Yeah. Not Therapists like Physiotherapists but people who are able to deliver programmes; so if people had a physio programme we have people who could work on that with them.

Interviewer: Okay. So, would a family for example hire their own private Physiotherapist and they would come in or how would it work?

Respondent: So, what would generally happen is we would refer to the NHS for a Physio or an OT to come out and do an assessment but then they provide generally a programme of care whether that’s daily exercise, whether that’s equipment that needs to be used, or whatever, and then our Carers will learn that and ensure that happens.

Interviewer: Okay, alright. And when you say you highlight that need to the NHS to whom would that…? I’m sorry; I’ve never worked in a care home in England.

Respondent: Yeah. We have a number for a referral team. We go to whoever the referral is. So, that could be Occupational Therapy so if a resident comes to the point where they need hoisting rather than being able to transfer for themselves we make a referral to OT for them to come and be assessed for a sling. If their swallow we worry is becoming unsafe we refer to the SALT team, the Speech and Language Team, so they would come and do a swallow assessment. So, we would do a modified diet; that kind of thing. Again within Psychology if we felt a resident needed more help with that then obviously the GP and things like that.

Interviewer: So, would that be like one a website, on a portal, for self-referring?

Respondent: Yeah. To be honest it’s a bit of a mess because everyone has a different way of contacting them. So, the OT is via a portal; wheelchair services have to be rung up, a direct line number. It’s a bit of a minefield because equally different Trusts have different ways of accessing so if that particular resident is funded by, say, [Place 1] it might be a different way of referring than [Place 2] and again different from [Place 3]. So, we really have to know who we are talking to and when and why.

Interviewer: How do you keep track of all of this?

Respondent: So, we know who are the commissioning body for each resident so then we look at that resident and then we just become familiar with… And we generally have three different ones: it’s generally either [Place 3] or [Place 2] or [Place 1] or, actually, [Place 4], or the NHS ICB. And their areas don’t necessary coincide with other areas so wheelchair services’ border, if you like, for who they cover is different from Occupational Health’s, is different from Speech and Language.

[0:09:25]

Interviewer: Okay. And is a resident only commissioned by one body or are they -?

Respondent: No. So, they can be joint-funded by NHS and Social Care which is often with Huntington’s. So, it’s generally between half ICB and half Social who will agree to pay a percentage of the costs.

Interviewer: A percentage; that is like 50%? How do you decide how much?

Respondent: They decide that. So, they will do their own assessments and they will decide how much they fund between them.

Interviewer: So, you have a person with HD; you see they are commissioned by NHS and Social Care, they need a Speech and Language Therapist so you make… well, however the path is to make a referral for Speech and Language Therapy which triggers something in the system that makes NHS and Social Care get back to you in terms of assessing what their percentage would be?

Respondent: No. So, for that again it depends. So, you go by the area that they are in. So, we would phone the [Place 3] Speech and Language Team or email them, they will then send back a letter saying they are very busy and to basically do what we feel our assessment is because, again, we are very used to it; they would then pick it up, they ask us a range of questions, and they will make an assessment over the phone mostly, and then you will find in a certain amount of weeks they may well come and do a visit, look at that person’s swallow, assess it themselves, and then confirm that. So, they rely on us to be over-cautious. So, it might be that we put someone with Huntington’s on a pureed diet for four or five weeks and when they come they say, “Oh yeah, there’s definitely an issue but we feel actually they can cope with a fork mash-able diet”, so we would upscale back up. But at least during that period of time we’ve been over-cautious rather than risk them choking.

Interviewer: Okay. And they are the ones reporting then to NHS and Social Care on how much work needs to be done with an individual?

Respondent: Yes. So, it usually would just go back within the health system. So, I don’t know what they then do for funding or charging but we will look at the area. So, because our care home is within the [Place 3] border that’s where we go by.

Interviewer: Okay, alright. Sorry to put you through this all.

Respondent: No.

Interviewer: Okay. And how do you feel that the patients with Huntington’s are different from your other patients? Is there anything you are more alert to in terms of… are they different somehow?

Respondent: They are more complex. Certainly the neurodegenerative illnesses are more complex because there seems to be 1) you have the comorbidities and the things that come along with Huntington’s, you have the lack of understanding from outside agencies and from other people, and you just have that decline that happens within Huntington’s which means you can get on top of something for a little while and then it changes and changes again. And equally the way different patients display very different needs as well; there’s not a one size fits all approach.

Interviewer: Okay. And when you make these referrals to other teams are they receptive or do you get a bit of…?

Respondent: We get quite a lot of dismissal; not from Speech and Language, that’s fine. From maybe wheelchair services; from the services that you want a piece of equipment or you want an assessment; where it becomes difficult is things like Psychology or other things where they will say, “Well, they’ve got HD; what do you expect?” and there is a little bit of casting aside people with Huntington’s because they almost feel they are a lost cause. You get that feeling in a lot of outside departments.

[0:14:56]

Interviewer: Okay, alright. And, if you don’t mind me going back to when I asked how you keep track of this all, so when you get new staff how do you teach these ropes? How does it work to…? Say you are only for a sabbatical for a month – wouldn’t that be nice? – what happens? How would people find information? Because I get that you have probably a lot on your head but is there anyone else apart from your head?

Respondent: Yeah. So, in terms of our new staff we do a period of shadowing and people are introduced to each of these residents. We have very detailed care plans which we do expect everyone to read. And they learn each individual’s needs and things. We put everyone on the Huntington’s awareness course that we do in-house and we also do with our Specialist Nurse, and she comes and trains them for us. And they just learn each of these individual’s needs. In terms of the management area, the supervisory role, that’s why we do have quite a large management team; so, we have our Head of Care and we have our Deputy Manager [Name 1] and myself who are all very much up on the inter-relational departments. Our Registered Manager has also had a huge amount of experience one to one with the individuals. And then our senior team are skilled in that area as well. So, we cascade a lot of the information so that there’s a back-up system.

Interviewer: And the care plans for example: does the care home have software they use or is it paper-based?

Respondent: Yeah. So, we’ve got software called OCM, Online Care Management, and yeah it’s all on a handset; so, we have it on the laptop base but Carers carry around a handset to input care notes, the care plans are on there and they can immediately get that information from there.

Interviewer: So, let’s say if the Specialist Nurse comes because you said, “This patient is getting more agitated; could you come and review?” she can see the medication or the report from the last shifts and things like that?

Respondent: Yes. She can see that and she can also see… we log any incidents or accidents on there. So, any episodes of agitation, any episodes or harm, any episodes of shouting, so any of that, are all logged and are flagged as incidents and if something is flagged as an incident it comes onto my screen so we can review it, myself and other management can review it, and we can collate it so if we see a pattern we can try and look into that pattern so we can say, “They are absolutely fine apart from every Wednesday afternoon”, and then I might say, “Well, who is one Wednesday afternoon and what are they doing?”, or actually if it’s not that and it’s every afternoon or it’s every this time or that time we can look at, say, medication or is there a reason for that. But it just helps to see patterns of behaviour and pinpoint where something is not quite going well.

Interviewer: That’s great. And can professionals coming into the home write on the system, because they don’t have a login?

Respondent: No. They can read anything from the system and we can input our Manager’s notes. So, if they feel they need to they can write a note on their and it just inserts into the daily notes of that particular resident.

Interviewer: Okay. Do you have a Doctor in-house?

Respondent: We don’t have a Doctor in-house but we have a Doctor at the local surgery who is very closely linked with us. He phones and visits if necessary every Wednesday afternoon and equally he has a good relationship with the Specialist Nurse and takes guidance from her, which is very useful because we’ve got that back-up if we need it.

[0:20:14]

Interviewer: Okay, that’s great. So, is this normal - I mean you’ll know other settings similar to yours – to have a GP linked to the care home?

Respondent: I don’t know whether it’s normal. Well, no, I do know it’s not that normal. I think it’s down to every individual GP who quickly found when he had a group of 30 complex needs young people it was much more convenient for us, and probably for him, to actually just come to the home rather than us all going down to them because we have quite a few people who need reviewing every week. So, it just made sense to have a list ready and for him to just pop out and see them.

Interviewer: Yeah. And this way, again looking at the Huntington’s patients, they are all under the same Specialist Nurse so it’s much more useful if they are under the same GP as well.

Respondent: Yeah.

Interviewer: Yeah, I didn’t think that was common; that’s why I was surprised.

Respondent: No, I don’t think so. But it seems to be a very sensible… and actually the fact that he obviously as a GP is very qualified in his role and very knowledgeable he has taken learning and instruction from the Nurse Specialist and will often consult her even for the medication reviews and things. And that’s really useful and I think she finds that very useful. And actually it makes a far better outcome for everybody because in that space she is the specialist so for him to listen is very really useful.

Interviewer: Yeah; which unfortunately is not widespread.

Respondent: Yeah. And he’s said in turn his knowledge of Huntington’s has massively increased because of the care home; we’ve got a real cross-section and it’s been valuable.

Interviewer: Yeah. I mean what’s the point in having 30 different GPs that have one patient with Huntington’s each that then you have to link with?

Respondent: Yeah.

Interviewer: It would be silly, yeah; okay. How is the interaction with relatives? How does it work?

Respondent: Quite diverse. So, we are quite an open care home; we welcome relatives at any reasonable time of day, we are really happy to have them be in the home and just sat around the home or to, if appropriate, take residents out; we are happy, if they are able to, to drop them off and things. We have a real cross-section of some residents who are sadly very rarely visited and some where the relatives are really very involved, so it’s quite diverse in that respect.

Interviewer: In the ones where the relatives are involved are they involved also on the care plan? I mean when a person is admitted for example how do you develop the care plan? What happens?

Respondent: Yes. So, if they are admitted from home if there are relatives to take information from we certainly utilise them and I think they feel a little bit more useful and empowered because I think there is probably a lot of emotional charge with putting your relative into care, generally people are at the end of their tether, they’ve tried to care for their loved one and they can’t do it anymore. There’s a lot of guilt and sadness with that so trying to make them as much part of that transition over tends to be 1) very helpful for us, and 2) helpful for them because they feel they are handing something over and they are being part of it. So, yeah, we get any information we can from them and we do kind of a pre-assessment, a pre-admission, checklist with them and we go through all the areas: communication, mobility, toileting, medication, that kind of thing, just to build up as much of a picture as we can. Some people sadly the family at that point have just disengaged completely and they’ve not been able to give us any information or even any contact for quite a long time, in which case we’ve either gone from hospital records or maybe they’ve been in a different care home for which they’ve had a care plan or domiciliary care where there’s been some kind of care plan. Some people we just have to write it as we go along.

[0:25:38]

Interviewer: As you get to know them; of course, yeah.

Respondent: Yeah. But particularly now we’ve been caring for people with Huntington’s for quite a while we have an almost template care plan for Huntington’s which we apply to everybody within that diagnosis ready for adaption. So, if they don’t have anything that goes in. And it’s immediate like taking time for them to respond, for processing speed, for not being too overwhelming, that kind of thing. So, there are things we’ve just learnt over time that need to be implemented in most cases. But, yeah, generally we like to have input from as many people as we can.

Interviewer: Yeah. And does it happen that sometimes this handover from outside to the care home is done by Social Workers or not?

Respondent: Yeah. So, Social Workers are involved particularly… I mean they are always involved but they do have to be more involved if family isn’t and sometimes they are a big part of it, which is generally due to the families not being able to.

Interviewer: Okay. Do you have a Social Worker at the home?

Respondent: No. So, each resident has either their own Social Worker or they have a Social Worker appointed for their placement. Sadly not anymore: people used to always have their own Social Worker but, as with a lot of things within the NHS or within Social Care, that’s not always the case anymore; but they will always have one appointed to facilitate a transfer or a move.

Interviewer: Okay. And that comes with their records who that person is or do you have to look for it?

Respondent: So, again generally if they’ve come from another care home, if they’ve come from hospital, we would generally get all of those records from the previous placement; and if they are coming from home they would come with everything, families would generally pass all of that information. Sometimes we do have to do some digging and some calling around but in general that information is provided.

Interviewer: And then they come to see the person or what’s their interaction while the person is at the care home?

Respondent: Of the Social Worker?

Interviewer: Yeah.

Respondent: Sometimes. So, they do an annual review because they are generally the funding body so I think it’s part of their stipulation. They will come when they are first placed. Some people very rarely see their Social Worker; some Social Workers will be involved for the placement and then not anymore, so then you don’t get any continuity with that.

Interviewer: Okay. And you’ve mentioned a couple of times that sometimes they might come from a nursing home or from another placement; does this happen often that they come already from a home, and why does that happen?

Respondent: Yeah. Quite often they come from another care home who don’t feel they are coping with their resident’s needs. Again Huntington’s is a complex need and I think a lot of other homes find it a little bit challenging to deal with.

Interviewer: Okay. You’ve mentioned [Place 2], [Place 4], [Place 3]; do you get residents from further away?

[0:30:01]

Respondent: We have had; we don’t currently. We’ve had someone from northeast [Place 5], one from [Place 6], and then out to the east. But in general they are within a one hundred mile area.

Interviewer: Yeah, okay. So, what do you find harder when juggling this complex care? Is there anything that is hard about it that is a different component into Huntington’s care?

Respondent: I think the delivery of the care is something that we are now skilled in and that is not so – it’s a challenge but it’s not difficult, just it’s one of those things. The difficulty comes with arguing with funders to provide adequate funding so we can staff adequately. It comes within fighting for resources for whether that’s a wheelchair or a bed or an assessment or things like that. That’s the struggle to us; that’s what is difficult is actually being the Advocate for these residents and making sure that their needs are met.

Interviewer: So, when you are being challenged basically on… you say, “This is what this person needs”, and they are like, “You are exaggerating”.

Respondent: Yeah.

Interviewer: Yeah, okay. Do you go like, “Well, you are invited to come in and see for yourself”? What happens? How do you paint the picture?

Respondent: The way they often deal with it is they ask us to provide sometimes up to two weeks’ worth of what is called 72 hour charts which is detailing every single minute interaction with that person, and they don’t take our really quite robust care notes. So, they wish it to be on their format in their way written in how they want it, which can take hours and hours and hours of somebody’s time to detail all of these things and then somebody looks at it and says, “Well, you don’t need three people for that; you can have one person”, or, “That shouldn’t take 45 minutes”, without actually having seen someone with profound (inaudible 0:32:59) movements trying to have a pad changed or changed multiple times in a day, covered in faeces, whatever it is, or even just moving from one place to another. They don’t have the insight and knowledge of Huntington’s to appreciate the complexities that go with it.

Interviewer: So, what do you think would help then in this situation?

Respondent: I think either education within the people who make these kinds of decisions or, if not, just an acceptance of the facts that we are reporting.

Interviewer: Don’t question the experts.

Respondent: Yeah.

Interviewer: Okay. So, when you say funding bodies you say quite a lot of them are funded by Social Care so I imagine you’re getting challenged by Social Care?

Respondent: Yeah. Literally at the moment we’ve got trying to reduce people’s packages, trying to reduce their one to one hours; and we’ve had to serve notice or we will have to serve notice because, “What you are asking us to do would not be safe. You are asking to withdraw care to the point where it’s not safe for this person”, which is incredibly frustrating.

Interviewer: And this is current?

Respondent: Yeah.

[0:34:30]

Interviewer: Okay, yeah. So, what you do basically is like, “I can’t keep the resident and the other residents and the staff safe with the request you are making so we need to move this resident somewhere else because they can’t stay here with the conditions you are demanding”?

Respondent: Yeah. And what is sad is those residents have come to us because we can provide that care. And they will ring round people, they will look for a cheaper provider, and they are highly unlikely to find one who will be able to provide the care. So, sometimes we do this really pointless exchange and they will do all of that, and then they will not find anyone and they will eventually put that money in; or they will and they will move this person to somewhere that is not equipped to cope with this resident’s level of need and you will see then that placement break down as well.

Interviewer: Yeah, okay. So, does it ever happen that you need to report these situations?

Respondent: Yes.

Interviewer: Yeah. Who would you report this to?

Respondent: So, what we have to do is give notice. I mean what we end up doing: we don’t cause a safeguarding because we put in the care at our own expense. We put in the care whether it’s funded or not, that’s what we do because we wouldn’t leave that person at that level. But we do find ourselves time and time again doing it without the back-up, without the funding back-up, that should be in place.

Interviewer: Yeah. But of course this goes in the background, right? They shouldn’t expect you to work for free or to add burden to your staff because…

Respondent: Yeah.

Interviewer: So, my question was can you report these situations particularly if there is a link of who is asking for it? Can it be reported to CQC? I have no idea of whom.

Respondent: Yeah. I mean it’s tricky because if we were to report ourselves to safeguarding they would say, “What are you doing that is unsafe?” and we would say, “Well, we are not because we are putting this in”, and what they will say to us is, “Well, then you tell them you can’t deliver the care at that level”, but of course all that does is get that resident then moved to a different place. It’s very much a business transaction to the commissioning bodies who can do what we want at the cheapest price. They don’t see the human behind all of this; they just see numbers and letters.

Interviewer: Okay. So, in my naïve view topic world it sounds like the CQC could go back to Social Services and say, “You’ve been asking this and this can’t be done so stop hassling and just keep providing the funding that you are supposed to provide”. It doesn’t work like that.

Respondent: Yeah; sadly no. The only time it can get a little bit more is if you get a multidisciplinary team – again, our lovely Nurse Advisor and maybe the GP and ourselves – all going at Social Services saying, “You can’t expect this; this is what this person needs. If you put them somewhere else they will not get this need and you will be failing them”. So, again it takes a huge amount of time and effort and input to put up that fight and that’s what has to happen almost every time. We currently have three people with Huntington’s that we are having to fight for their level of care.

Interviewer: Okay. So, I mean apart from the direct care you have to provide you need to spend a lot of resources to make sure you keep providing the care that is needed.

Respondent: Yes.

Interviewer: Okay.

[0:39:16]

Respondent: And of course as staff wages go up that all has to uplift. And this is across all of Social Care, this isn’t specific to Huntington’s, but the uplift that the health and social care world will get in response to the national minimum wage is nowhere near what the wage increase is. So, everyone will be trying to find where they pay their staff the amount of money which has gone into everything else.

Interviewer: Yeah. So, let’s brainstorm a bit here: so, you somehow through experience got the conclusion that it was more efficient and everybody would win if there was one GP to look after your 10 HD residents.

Respondent: Yeah.

Interviewer: But somehow each HD patient you have is linked to their own Social Worker or their own funding body and again it happens that they have sparse people with HD, they don’t realise what it means, and then they challenge the decisions; would it not be easier to have… I mean, as you are saying, this is not even just a Huntington’s problem; I mean I can imagine this happens if you have a patient with Parkinson’s or anyone receiving funding basically, they will try to cut it.

Respondent: Yeah.

Interviewer: I think what we are discussing is it is more likely that other placements are less competent to care for people with HD.

Respondent: Yes. And I think that’s where that differs because you have far more of a… if you’ve got someone with a dementia or you’ve got someone with a learning disability, yes, we can provide that care but so can a lot of other people so we will state our fee and it’s quite clear cut: either people want that or they don’t that and they can go to other places. It gets frustrating when we know, we’ve built up this expertise, we know that other people struggle greatly with these residents and yet they are still arguing. And that bit is specific to HD because we equally know around us there is nowhere else who will be able to do the job in the same way.

Interviewer: Because I’ve been talking to a lot of people and I’ve worked in this area for a long time the way I see it what happens is this person gets moved to a cheaper nursing home that then can’t cope so it ether goes back to you for example or gets admitted to hospital because there is a crisis and then certainly to stay at the hospital is more expensive than to have just kept the person as he was, so it’s not even smart even if they do look at money. So, is it because you think the owners moved from being paid from Social Services to being paid by Health because it does change then?

Respondent: Yeah, it’s different pots of money and it’s also different person’s funding; it could even be a different financial year. So, even if they can put something off for a few months they can offload the problem for that amount of time. I think also they’re not aware of the complexities so they think, “Well, that nursing home: they do nursing, there are Nurses there; they should be fine”, and feel that that is fine to do. And again, yes, once they’ve gone into hospital then that’s Health’s budget; that is Health’s problem. I do think there are some times again with Nursing medication can be used – to me immorally but – as a way to stop people being a problem; so, dosed up half asleep kind of thing. So, maybe a nursing home has got more scope for that but that is not our way of doing things. But maybe they feel that that is effective.

Interviewer: Probably cheaper.

Respondent: Yeah.

Interviewer: It depends on what they measure as success, right?

Respondent: Exactly, yeah. However with people who are more sleepy then you will get more skin integrity issues, you get more bed sores; you get all of that that goes with that as well. But there’s just not the voice or the support services, you know? Even within dementia you’ve got huge amounts of bodies that advocate for people with dementia; Huntington’s is such a specialist area that people don’t know about people don’t have those insights and skills.

[0:45:15]

Interviewer: Yeah. And I mean the good thing here is it sounds like when you are a crossroads with a patient you know that you can contact the Specialist Nurse to come in.

Respondent: Yeah.

Interviewer: So, there is already a line created there. Why can’t we have a Social Worker allocated to the patients like the GP is?

Respondent: I think because Social Care is not in our… they are their own body, they are their own rules. They don’t have enough Social Workers for every single person who needs a Social Worker so they are just allocated as and when a particular need arises. They would through that piece of work and then they are sent off to deal with someone else and something else.

Interviewer: Okay. This is something for me to discuss with a Social Worker if I can find one who will speak to me, which is proving impossible. I will email you after this and ask, “Is there a Social Worker that you know?” I never tell people how I came up with their contact, I just say, “I’m aware that you’re supporting or that you’ve supported people with Huntington’s”; so, I will email after and I will ask, and then you can have a think. They don’t have to be good Social Workers; they don’t have to experts in Huntington’s; they just need to have had some contact with Huntington’s and be a Social Worker.

Respondent: I think they go through very much a learning curve when they support people with Huntington’s because they have to very quickly – I am thinking of one in particular who has supported a lady from being in her house and that going very wrong to the mental health team feeling that she didn’t need residential care, then when they felt she did they didn’t want to have her hospitalised first and this Social Worker having to deal with all of this. Then it came to a point where she very much did need hospitalisation. And we kind of had to say, “We will absolutely meet her needs but she does need a period of hospitalisation first”, and then that Social Worker having to go into her house and remove this lady with the police into hospital, remove her from her family, and then finally to us. So, although that Social Worker was currently associated to this lady she now triggers our residents so much so that she invokes behaviours in her because she sees her as, “This person is a bad guy; this is the person who has caused all this problem”. So, the last time we did have to ask her not to come and see her; we would see her obviously in our office, but not to agitate her by visiting her.

Interviewer: Well, they don’t gain anything through that.

Respondent: No.

Interviewer: Yeah. So, I mean she’s a trigger at this point because she’s associated with a bad experience, yeah.

Respondent: Yeah. And I think that’s not necessarily her fault but she’s the link between all of those stages that our resident sees as the reason. And I think they are fighting the same things because they are the ones asking for the funding, they are the ones asking for this, that, and the other, and they hit as many walls as we do. So, they can be good ones, they can be bad ones, whatever, but they are probably just as frustrated.

Interviewer: Yeah. It’s not an individual problem; it’s a system problem.

Respondent: Yes.

Interviewer: The same way it’s not a Huntington’s problem; it’s a system problem.

[0:49:19]

Respondent: Yeah.

Interviewer: Yeah, okay. Because this happens then with other residents; Huntington’s are not… I mean challenging their needs basically, their funding needs?

Respondent: Yeah. It does happen with other residents; it happens far more with Huntington’s.

Interviewer: Okay. And do you think again because it’s a rare disease, there are a lot of mental health problems associated, and because this just simply doesn’t fit with people’s knowledge they disregard?

Respondent: Yeah.

Interviewer: Okay. Do you connect with the mental health teams or is there any need?

Respondent: To be honest we go to our Specialist Nurse.

Interviewer: Yeah; that’s what I was thinking, yeah.

Respondent: We’ve been given, particularly with one of our residents, contact details for them but we know actually that our Nurse is going to have more knowledge than that team because actually it’s that team that made the assessment that, “Oh no, this would be fine and this would be fine”, when I could’ve told you it wasn’t. So, it’s not to negate their skills in other areas but, again, with Huntington’s it’s just we’re best off with our Nurse.

Interviewer: Yeah, okay; good. I love [Name 2] as well; I’m a [Name 2] fan, but I should be completely impartial but how can I be?

Respondent: Exactly.

Interviewer: Now is she enough though? That’s the question. Again is this just not an individual… yeah.

Respondent: Well, the problem is I don’t think there’s anyone to replace her and that’s the worrying thing.

Interviewer: I worry as well, yeah.

Respondent: Yeah, that is the big concern. And I think that’s why she tries to pour all of her knowledge into us. But, no, it is a concern.

Interviewer: I’m sure a lot goes into the training and keeping… this goes across all care contexts: the rotation of staff, staff changing; and I imagine you ring her and it’s like, “Well, we have five newcomers; it’s time for a refresher”.

Respondent: Yeah.

Interviewer: Okay. [Name of Respondent], the nursing home pays for the training?

Respondent: What? That [Name 2] does? No. She comes and does it, I don’t know, in her time. She doesn’t charge for the training she does.

Interviewer: Okay. And does it happen that… Again I was saying she’s one Nurse part-time and she certainly does all she can; do we need more?

Respondent: Yes.

Interviewer: Yeah, okay.

[0:52:42]

Respondent: Yeah; because, as you say, she’s one woman on her own - she’s not old but she’s equally not young – who used to have a much bigger team I believe that now doesn’t have a bigger team, who doesn’t seem to have anyone coming up to replace her and these needs are not going away, these needs are complex. And I think we desperately need people invested and she needs investing in, and she needs backing up and supporting.

Interviewer: Yeah. I would sleep better at night to know there’s a baby [Name 2] going around being trained.

Respondent: Yeah. As I said, the best we can do is be the base and support and things. And, to be honest, we have plans hopefully in our future to be a specialist centre from the point of diagnosis. So, we have our kind of five to ten year plan of us to be able to open on this site a clinical area, a day centre, that kind of thing, with much more robust support; maybe have space for clinics and things like that. We’ve got that space and we’ve got the drive to do it, but we would need people to come and support us to make that building happen and to have the people to be the specialists within it.

Interviewer: That’s it; I’m packing my bags and I’m moving back to England. Yeah, I think that’s a wonderful idea. I mean you’ll never run out of clients; that’s for sure.

Respondent: Yeah, exactly.

Interviewer: Yeah, okay; alright, good.

Respondent: And I think because of the familial pattern within Huntington’s – I’m kind of going off on a tangent here – we have had a lady about eight years ago now, we have her brother, we are about to admit her sister, and their mother passed away with Huntington’s. So, you can see the pattern through. We’ve got two sisters in at the moment and we’ve also got people here that when relatives come and visit you can spot signs or relatives are going through testing and things like that. And I just think although from a point of diagnosis there may be quite a while where people don’t need inn-patient care they should have access to support and maybe if we could de-mystify that kind of journey and be a phone support or be somewhere people can come and do aerobics together or yoga together or cooking or something in the very early stages people can be a support network, or their families can come and their friends can come for information, that kind of thing. Maybe some of the mental health issues that come alongside it can be minimised to a greater extent if there’s that access to that therapy and that kind of group support which, again, people with Alzheimer’s seem to have; people with that kind of thing seem to get a lot more. I know there’s a Huntington’s Disease Society but to have a place where people can do that, that’s what I’d like to make happen.

Interviewer: I mean I think your point is really important because what you’re saying is that either way you’re working across generations not just at the point that they are admitted but actually you can spot on visitors certain changes so you are spending more time with the relatives than the GP or the Geneticist is spending potentially with those people. So, it would all be within the same hub, which sounds really exciting. Yeah, that’s an excellent idea.

Respondent: A Geneticist can give you, “This is your diagnosis”, okay; a Therapist can give people counselling, that’s great; but actually what people might want – and we’ve talked of this with [Name 2] – they might want an hour’s phone call, they then might not feel the need to engage with anything more for a year, five years, whatever but to know that this place is here so they go, “Right, I don’t want to go and see the end stage but I might go and do a cooking class with five other people who are five years into their Huntington’s diagnosis”, or with their brothers and sisters or with their families, “So I can dip my toe in without it being too scary”, or to talk about the frustrations. To have that point where they can ease in without it being so isolating, because that’s the big thing that we hear is families are being very isolated and it’s a terrifying prospect if particularly you’ve seen your mother or your other family members and then you get that diagnosis; they could really do with that support.

[0:58:42]

Interviewer: Yeah. And we get that from the support groups, not just Huntington’s; it’s described that people don’t want to… like someone at risk or positive but asymptomatic doesn’t want to be sitting across someone 20 years into their HD diagnosis. But again that’s a very formal and a very much, “You are here for this”, type of forum instead of what you are discussing which is putting a positive spin onto living with a disease that is chronic.

Respondent: Yeah; completely.

Interviewer: Okay, alright. So, do you think that we need something to make services more connected or sectors more connected?

Respondent: Yes. I think we’ve all got a little bit disillusioned with the NHS and the services in general and how that works. And I think the bottom line is there is a battle for resources, there are only so many resources. We’re aware of that. There is only so much funding, there is only so much money, and therefore the fight: you just have to be the loudest and the pushiest, and that’s just the way it has happened. What I think is when there’s something complex people either need to be educated or to listen to the people who are, and I think that’s where it goes. And even if we have to provide… our audits show that we are delivering consistency and that we are not inflating things like you say, “Come and visit; come and see a day in the life of this person” if necessary that would be your proof rather than hours and hours and hours of fighting over whether this person needs three people or four people or whatever they do. Yeah, I don’t know how it would fix it but yes.

Interviewer: I already discussed today the need for people to come and just spend a bit of time here and then you’ll see, “There’s your proof”.

Respondent: Yeah.

Interviewer: Yeah, it’s interesting that I’m going over the same topic on the same day. I’m not a great Bible quote type of person but there was one of them that, “Need to see to believe”, isn’t it? So, there you go.

Respondent: Well, that’s it. And I think if everyone is telling you the same thing it might just be true, you know? And the work; the extra work that goes into making these proofs is ridiculous. Our Manager the other night spent eight hours after work filling in two weeks of these care plans for it to be immediately rejected.

Interviewer: Oh god, no; really?

Respondent: Yeah, because the quote was, “They don’t even have anything complex like a feeding tube”. How much more complex do you want to get than…

Interviewer: Yeah, okay; alright.

Respondent: Some of our residents can’t have a standard bed because of their movements and they kick the beds apart, they crack holes in the walls, they can’t help any of it. The black eyes half of our Carers have got… And again it’s not behavioural and we get told, “Oh, it’s behavioural”; it’s not behavioural, they’re not kicking you because they’re cross.

Interviewer: No. They’re not aiming for your eye; they’re not aiming at all, they just can’t stop it, yeah.

Respondent: Yeah. And they said, “Why do you need four of them to change their pants?” “Well, come and look; you’ll see why we need four”, you know?

Interviewer: Pure ignorance.

[1:03:11]

Respondent: Yes.

Interviewer: Okay, nearly done. Okay, I’m going to do a set of boring questions now that I ask everyone. How old are you?

[redacted]

Interviewer: Okay. [Name of Respondent], is there anything that I have missed from our conversation that you thought, “Oh, I thought she was going to ask me this and she didn’t ask me this”?

Respondent: No. I think I’ve ranted enough.

Interviewer: Well, you’ve ranted as much as I asked you to. I’ve prompted your ranting. Okay, do you have any suggestions in terms of future improvements for me to manage with other participants in terms of our communication?

Respondent: No. I think it’s good to move through that process. And I think the highlight is actually – I don’t know about anyone else but for us specifically – it’s not the needs of the patient that are challenging, it’s getting them the resources they need.

Interviewer: Yeah. That’s what is being more time-consuming and stealing you away from what you should be doing in the first place, yeah.

Respondent: Yeah.

Interviewer: I meant to ask you, [Name of Respondent]: have you ever had an MP or someone coming and, again, seeing? I know the Huntington’s Association for example went to Parliament last year in May or something; I was wondering in terms of when we spoke about the different pots of money and how patients are commissioned has it ever happened that someone has come?

Respondent: Not with an MP, no. I do know we managed to get into the mental health teams a review of their treatment with people with Huntington’s because of their absolute failure to provide a certain resident with the appropriate input based on their ignorance of Huntington’s. So, I know that went on; that’s been up-scaled, but again it was in one particular department within [Place 1] but each individual place is a learning curve. So, no; we’ve done it within Health but not with an MP.

Interviewer: Okay. I was just thinking, yeah, because it seems like a lot of it is money as well.

Respondent: Yeah.

[redacted]

[End of Transcript]