[0:00:00]

Interviewer: [redacted] so can we start… if you tell me a bit about your current role please?

Respondent: Okay. I’m a registered Mental Health Nurse and I’m a Clinical Nurse Specialist working with people with [redacted] dementia and Huntington’s Disease. I’m based at [Location 1], but my role is mainly in people’s homes seeing people in the community who maybe can’t get to the hospital for a clinic or who need support between clinic visits. So, I’m at the hospital very little – really only for clinics – most of my work is done in the community seeing people in their own homes or in care homes, residential settings, other hospitals. I do a lot of work with GPs and care homes and families who live with somebody or who are close to somebody with Huntington’s Disease.

Interviewer: Okay. That’s quite a lot already. So, with the clinics how often are the clinics happening at the moment?

Respondent: Since the pandemic everything changed at pandemic time. So, we used to have four or five clinics a year which would be a big group of people; there would be myself and one or two Doctors maybe, there would be Nurses from the research department, there would be someone from Genetics, somebody from the Huntington’s Disease Association; a multidisciplinary team. The pandemic stopped us doing all that so now that that’s all hopefully settled down we’ve kind of regrouped into a bi-disciplinary clinic so with the rest of it available virtually or as needed. So, what we do now is we have more clinic opportunities with two Consultants, we have roughly one a month, and it’s just the Consultant and me. So, what happens now is that when we get a referral to the Huntington’s Disease clinic I will contact the patient and go out to see them if that’s what they want – I mean not everybody wants to see me – but I’ll usually go out and see them at home and kind of make some judgment as to what we need to do next, and that’s usually to refer them for a neuropsychology assessment and an MRI, and then when those results are back then I book them into the clinic to see the next available Consultant. So, they’ve been seen by me and I’ve initiated anything that might need to be started for example referral to Social Services or treatment for any other co-existing conditions. And then when the Consultant sees them they’ve got the history, they’ve got my interpretation, they’ve got hopefully a neuropsychology report, and an MRI so that meeting with them is a bit more fruitful I think than it used to be. They used to come and then we’d do the neuropsychology so we’re doing it slightly the other way around. So, when people come to us they’ve already got a diagnosis; they’re not waiting for any diagnosis at all, that’s already been done. So, this is about supporting people from the diagnostic point onwards. So, there’s less of a rush to get everybody in the clinic at the same time; most people have already seen Genetics, most people know the Huntington’s Disease Association, most people know about research or they know that it exists. So, my role really is sort of putting it all together a little before and after the clinic and from that point on the person is invited to keep - or their family – contact with me, and if they need to come back to the clinic to see the specialist because of a significant change in condition or a co-existing condition or any medical legal issues or areas of great concern or risk I’ll put them back into the clinic. But otherwise we deal with a lot of stuff remotely. So, I’ll go and see them at home; I’ll liaise with the GP; I’ll work with mental health teams or whoever else might be involved. The tradition of seeing them annually was really not always helpful. People wanted the contact with the clinic; they didn’t want to lose that annual appointment because that was their contact with people who understood Huntington’s Disease, but actually I think what we’ve got now is better in the sense that they get contact fairly quickly after the referral has been received, we then do examinations and assessments, then they see the Consultant. And they can back in and out of that as needed but it’s kind of done through me. So, as an example, I’ve had some phone calls in the last day or two from a wife of a person with Huntington’s who is worried about his changing abilities and so forth; they don’t need to wait six months to see a Consultant, I can go out and have a look, I can liaise with the Consultant if need be. So, we’re doing it slightly differently. It was a whole multidisciplinary team; it’s not now. But they are accessible. They know when the dates are. If there is somebody that actually says, “I really want to talk to Genetics about them”, we’ll ask them to come and join us, but usually it’s just me and a Consultant and we feed out from there whatever is necessary to be done. Does that make sense? And we’ve just moved away from the rote annual review; we’ve got also far too many… there are so many referrals it would be really difficult just to keep up that annual review.

[0:06:25]

Interviewer: Where are the referrals coming from?

Respondent: They are mostly coming from Genetics or from GPs or from people who are no longer able to travel to UCL for example. Lots of people are seen in London; there comes a point when actually that journey to London is very difficult for people so they then transfer back to [Location 2]. So, mostly from Genetics but I suppose it’s 50/50 maybe primary care when the person has got maybe some mood problems or cognitive problems that the GP might need advice on. That’s generally where the most referrals come from, or a few from other Consultants where the patient has been referred to a different clinic and they’ve been passed over to us.

Interviewer: So, [Name of Respondent], I mean I understand how the Genetics team work so closely with you so they find the way to you very easily, but with the GPs how do they know it’s you or how do they find their way to you from primary care? Do they Google or what happens?

Respondent: I don’t know actually; maybe they do. Well, there’s stuff on the website isn’t there to find us? If you type, “Huntington’s Disease clinic”, into Google in [Location 2] you’ll get us popping up. And also over time we’ve built up a bit of a reputation so quite often people phone up and say, “I know you do HD; how do I refer somebody to you?” or I might be seeing other family members and then somebody else crops up and needs some input. So, some of it is word of mouth; some of it is reputation. But it should be fairly easy to find us. I mean I think the website is not bad and patients will go to a GP saying, “I want to see the Huntington’s clinics. I think it’s time I went to the Huntington’s clinic”, and it’s not rocket science to work that out. Plus we’ve got an HD care pathway which is for GPs or any other professional to be honest to refer to. All the contact numbers are on there, all the dos and don’ts of who we do see and who we don’t see. That’s all there for them to access.

Interviewer: That’s on the website?

Respondent: Yeah, it is; yeah.

Interviewer: Okay. So, in the GP does a patient at risk or with a family affected by Huntington’s would they have any label or something to say that they are potentially at risk of Huntington’s in the terms of the system? Because I remember patients with epilepsy and multiple sclerosis they have this code but if they are still just at risk and under Genetics just receiving counselling is there anything that the GP can see?

Respondent: I don’t think so because I’ve asked a few GPs that if somebody’s mum for example has HD would the son for example be flagged up as a child of somebody with Huntington’s Disease and the answer so far has been no. I don’t know when they are tested if that changes the way that GP or primary care data is collected, but as far as I know it’s not that obvious. If the patients says that’s the story that’s a different matter, but I don’t think they are automatically flagged up as potentially being at risk or that that would explain the reason why they are presenting to a surgery now. So, somebody who is at risk may present to the GP with sleep problems or anxiety problems; if you know that that person is at risk then you would manage it a different way, you would send them straight to us. So, it’s kind of important that we get these people at the point of testing and say to them, “Any question give me a ring and if I think it’s something you need to see the GP about we’ll advise you”, but we can advise on that kind of stuff so that they’re not stuck in that dead zone really where they don’t know where to go.

[0:10:53]

Interviewer: Yeah. And I spoke this week with a chap that one of his relatives is refusing to be tested and this relative isn’t in [Location 2], but he was saying he can only access the services if he has a diagnosis and he refuses to be tested so we can’t get him through; do you have that in your experience?

Respondent: That does crop up sometimes and it’s a very difficult one to try and address. It depends how it raises really. So, if the person who is perhaps manifesting HD symptoms but they’ve not been confirmed then we aren’t able to get them in the clinic, but I might be able to talk to their GP about managing some of the problems that they are presenting with. So, I’m doing it from an HD point of view – general advice it would be – I might be able to suggest some things. For example, people who complain of sleep problems or irritability and poor impulse control that respond to treatment, but if I can suggest that to the GP that sometimes works doing it in a back-handed way. If the person can get to a GP and I can get to the GP we might be able to come up with something there. The other thing that I sometimes do is talking to, say, the child – like your example – and kind of talking to them about what might help treatment-wise or what could be done maybe supports them a bit better in talking to the person who is affected and who is really unwell at the moment. It is difficult and I’m never quite sure how you completely solve that problem, but sometimes you can if you’re a little bit abstract in how you get to the patient through other people. Yeah, it’s very difficult; you can’t make people have a test.

Interviewer: Yeah. I feel reassured about all the training you gave me, it gave some fruit because I was like, “Well, I’m not here to provide clinical advice but…”

Respondent: We know stuff, yeah.

Interviewer: But, yeah, I thought it was as you mentioned the HD clinical pathway that we sort of suppose people have been tested and they are engaging, but I guess of course you get plenty of people that are not engaging and then it’s critical to act. Okay. So, [Name of Respondent], can you tell me a bit about your past training before you started as a Huntington’s Disease Consultant? What has helped you in managing Huntington’s patients?

Respondent: Sure. Well, I qualified as a Mental Health Nurse in [year] – it was a long time ago now – and working in mental health I did all the forensic and acute and adult and all of that kind of stuff and got very interested in dementia care because Psychiatry has a bit of a reputation for being a bit abstract and I liked the fact that in dementia you could scan somebody for example and see what the problem is – most of the time, not all of the time; it’s not always that clear – but you could say, “Oh, there’s the stroke and the stroke has happened in the left parietal lobe”, so then you kind of know what might happen to that person or how the behaviours might change. So, most of my clinical work was done on dementia and I got around dementia in-patient units and day hospitals and all the service altogether, but then got very interested having had a person admitted who was only 45. I realised how badly – with the best will in the world, but how badly – set-up we were for anybody who was younger. He was quite an impaired gentleman but we had nothing; we had no leaflets, no nothing, no information, no toys for the children who visited to play with, all this kind of… when you’re working in a hospital. We had nothing. We meant well and did well, we did the best we could, but it was very unprepared. So, at that point I kind of got interested in auditing how many younger people there were with cognitive problems coming into the psychiatric service and that’s where you pick up people with Huntington’s Disease because they’ve got cognitive problems but it’s their behaviour that’s brought them into psychiatric care. So, interestingly I helped set up a service for younger people with cognitive problems and we sort of supported them at home in terms of their mental health, but had quite a few people with Huntington’s Disease. And I was always struck by a) how complex they were, and b) how nobody wanted to deal with them, and how people saw them as somehow nothing to do with mental health – and there’s a reason for that which I’ll explain in a minute. So, I thought people who had very clear depression for example were not getting treated because people were saying, “Well, that’s what happens in Huntington’s”, and it is but you can treat it. It’s a bit like saying somebody with cancer who has a lot of pain saying, “Well, that’s what happens; you’ve got cancer”, but you wouldn’t do that; you’d make every effort you could to try and get that pain under control if you could. But there’s a different set of parameters really that something in a neurodegenerative disease I think a lot of healthcare professionals and families think, “Well, there’s nothing much you can do; that is HD”. And I saw so many people get better – and in things like dementia as well, Alzheimer’s Disease – I saw them get better with the right treatment. So, I came across many people who had been admitted to hospital in a very distressed state and not looking after themselves very well, very agitated, not eating properly, not sleeping, quite distressed; and with the right treatment that all settled down and, yes, they still needed care and support and someone else to do the cooking and look after them but their quality of life just improved considerably. And I thought, “Well, why doesn’t this happen with Huntington’s Disease?” And I did a bit of a survey in the big psychiatric service where I worked before. I went around to all the adult psychiatric admission units – so, people under 65 who were admitted – and without exception every single one of them said, “Oh, yeah, we had a person with Huntington’s Disease; what a nightmare”. They all had somebody they had looked after before that stuck in their heads as being really difficult, really distressed, there for months, and nobody knew how to manage them. And I thought, “That’s just striking that everywhere you go every unit had a memory of a person with HD”. So, I just got very interested in it and the service that I then worked for was closed and then I got the job at [Location 2] and was able to then pick that back up again. It’s a disease that people are frightened of I think, a disease that nobody really knows apart from us that really know it well that know about handling it. Whoever you speak to: GPs, Consultants, District Nurses, anybody, they will all say, “Well, I had somebody with HD once but they weren’t like this; they were very disabled, they were in bed, they were needing feeding and all that kind of stuff; we’d never seen this before”. So, I think there’s quite a big group of people who are not getting optimum care because people don’t spot it for what it is and maybe don’t recognise that actually some of those symptoms maybe can be treated. Now in mental health the Mental Health Act says that you can’t admit somebody to hospital under the Mental Health Act – so, therefore, against their will – for a physical illness, and that’s a big part of the problem. So, if they had appendicitis and they said, “No thanks, I don’t want any surgery. Leave me alone”, you can’t admit somebody under the Mental Health Act for that reason. Now we know that if you don’t address appendicitis the person will get very sick and may die, but if the person has made a judgment in sound mind at that time – odd but sound – we have to respect that and we can’t section somebody to a general hospital to have the surgery that they badly need. And the same applies, as people read it, to… they see Huntington’s Disease as a neurological condition and therefore nothing to do with psychiatry so they will say, “Lots of people think it’s a neurology problem; we can’t admit them for that, they should be admitted to neurology”, well that’s not the best place to look after somebody with Huntington’s Disease who is very distressed. What I try to say to people is that the Mental Health Act says you can admit somebody to hospital for treatment of their mental disorder, but they don’t see that as part of Huntington’s Disease that is treatable. Does that make sense?

[0:21:05]

Interviewer: It does. But, as you’re saying, it’s part of the problem that the mental health side isn’t seen as something intrinsic to the condition which just blocks. So, if a person says, “But I’m fine”, or, “I’m doing well”, so they’re like, “I mean they are fine so there’s no problem, right? So, we’re going to just move on”, while, as we’ve discussed before, then you have Carers just going like, “But, no, nothing of this is fine”.

Respondent: Yeah. So, I think the Mental Health Act partly gets in the way of that, yeah.

Interviewer: But this is interesting. I mean I think it’s sort of like the first time policy comes into the game because it’s blocking people from getting the care they need.

Respondent: It certainly is on occasions, yeah.

[0:22:15]

Interviewer: So, I mean do you see this with conditions because you also look after [redacted] on-set dementia? Do you see the Mental Health Act also impacts on them?

Respondent: Not really because that’s a dementia so people will say, “Well, dementia is a mental health problem”, it’s an organic one the same as HD and the same as schizophrenia, that’s an organic brain condition, but people have very different values when something happens to a [redacted] person with dementia. So, say if they have young on-set Alzheimer’s Disease or frontal temporal dementia mental health services and most people will say, “Oh isn’t that awful? That man is only 50 years old and he’s got a dementia; we must do what we can”, and that person is more likely to get the right treatment or be admitted to hospital – maybe against their will but they will see that as a mental health problem – they don’t see that in Huntington’s Disease is my view. I mean I stand to be corrected but there’s a lot of, “It’s a neurological problem; send the person to a Neurologist”, and Neurologists will say, “We don’t know to manage the mental health; that’s not what we do, that’s not appropriate”, and it isn’t appropriate. So, there’s something about dementia is okay, a person with Huntington’s Disease goes to Neurology. It’s as black and white as that to some people. So, I’ve been in psychiatric ward reviews where somebody with HD has been admitted with very distressed and agitated behaviour and people are sometimes quite cross that I’m not saying, “Well, we’ll take them into the General Hospital; don’t you worry”. And they say, “This person shouldn’t be on our ward; we’re not set up for these neurological problems. It’s nothing to do with us. We don’t do Huntington’s Disease”, and I say, “But you do do anxiety and you do do suicidal behaviour and depression; you do that bit I’ll do the rest. We’ll sort out the other bits, but if you can tackle that low mood, that person’s agitation and anxiety, which you’re good at doing that’s what we’re asking you to do. We’re not asking you to do the Huntington’s bit as such, we’re asking you to do the mental health bit and that bit research says is amenable to treatment the same as in anybody else, i.e. some people will respond really well to the first drug you try and they’ll only be in hospital for a couple of weeks maybe, some people are very resistant and take months in hospital; that’s the way it is”. That’s the way that’s always been; you get some patients who take a long time to fix. But all HD people take a long time to fix if you don’t start them on the right treatment. So, it’s a very strange thing that I battle with fairly regularly trying to convince mental health units to prescribe treatment that they think is not warranted.

Interviewer: Okay.

Respondent: An example of that might be I will say, “That person’s anxiety and agitation I think will calm down if you prescribe an anti-depressant”, and they will say, “Well, we’ve asked him if he’s depressed and he says no. he’s not crying, he’s not sad”, and I say, “I hear what you’re saying but you’re looking at a whole set of biological features of depression; look at that. That person is not eating, they’re agitated, they’re not sleeping well, they are irritable, they are grumpy, they can’t focus, they are very distressed; that’s depression without the words”. So, mental health services rely on people saying, “Oh, I feel dreadful; oh, I feel really anxious”, and things that you can rate. “I felt number 10 on the anxiety scale before the treatment and now I’m down to 2 so it’s working.” And you can’t do that with an organic condition so well. So, my granddaughter refers to, “Your listening ears and your looking eyes, Nanny”, and I think if people could look at what’s in front of them and listen, as my [less than five] year old granddaughter says, they would see it slightly differently. All the symptoms are there if you look for them.

Interviewer: If it walks like a duck, quacks like a duck, then it’s not saying it’s a duck though so maybe it’s not a duck. I guess that their perspective, okay. So, is there a Psychiatrist or a Neuropsychiatrist at [local hospital]?

Respondent: There is a neuropsychiatrist in the liaison service but they don’t have anything to do with the HD service so that’s about seeing people who present with overdoses or agitation and that kind of stuff, so they’ll deal with that but they are not part of the HD service. We are kind of running on slippery ground really.

Interviewer: Because you have the expertise?

[0:27:45]

Respondent: Yeah. I mean that’s sitting with us for now. In an ideal world of course you’d have a Neuropsychiatrist, you’d have a Social Worker, you’d have a Physio, you’d have an OT, you’d have a lot of people. In a way that’s okay because if somebody is living at home those services to deal with OT issues or Physio issues or swallowing issues, diet, that’s all there; you can refer people to those specialism and they will deal with people with Huntington’s Disease, that’s what they do. But it’s the mental health bit and the cognitive bit that is most challenging to deal with, and very few resources to actually manage that. So, yeah, in an ideal world you’d have a Neuropsychologist. There is a Neuropsychologist; not a Neuropsychiatrist, we don’t have one yeah.

Interviewer: Okay. And how do you see this ignorance, for lack of a better word, lack of acknowledgment of all these mental health problems that Huntington’s Disease has affecting in terms of people’s social care needs? So, we’ve talked health so far; how does it impact on a social level or dealing with social care workers?

Respondent: I think in terms of how to support somebody with HD at home you’ve got a very similar issue there sometimes with social services and they will say, “Well, the person doesn’t need taken to the toilet, they can feed themselves, so there’s no need for us to be involved”. I’m quite good at calling collective meetings, multidisciplinary meetings, so if you’ve got a Social Worker involved and GP, “Let’s get all around the table at some point to try and make a plan about how to manage somebody long-term”, because Social Workers also haven’t come across Huntington’s Disease very much and they will have their own set of beliefs about somebody who doesn’t engage with services. For example, we’ve talked in the past about a person’s lack of insight so I do visit people who are living in awful conditions with unsafe housing, dirty housing, neglected housing, the person is neglected, they are not eating properly, you can see that the house is in a total mess, and social services will often say, “Well, that’s their choice; they’ve made a choice to live like that”. So, they don’t see that that person is insight-less maybe and is not able to envisage or recognise what’s happening to them or what will happen to them in the future. So, somebody who’s got HD is very symptomatic and has quite a lot of problems will eventually escalate up the system and end up in Health or causing concern to social services because they can’t live at home anymore and they need placement. And then there are very few places that take somebody who is very restless or distressed or aggressive. Then they come to me and say – I’ll give you an example: a chap recently who was moved; this was his fifth nursing home placement in our area and they said, “He’s got to go; we’ve given him notice to leave. He’s aggressive; he shouts at people, he’s hit staff”. So, the fifth move to a care home. So, when I went to see him he quite clearly told me he didn’t know why he was moved from home to home. He’d lost his girlfriend because she was living at the previous property. He had a cat which he brought with him and the home said, “You can’t have a cat; we’ll take the cat away”, so he lost his cat, he lost his girlfriend, he lost his property. So, he was uprooted yet again and untreated so he was angry. And he said, “Oh, I hit people and I don’t meant to; it’s horrible, I shouldn’t be like that, they don’t deserve that but they wind me up”. So, there were lots of meetings to say, “He needs to go to a secure unit, this is the fifth home he’s been in, no home could cope with him, he just gets really violent and the police have brought him back once or twice, he’s drinking alcohol; a bit of a nightmare”. So, we got him on an anti-depressant and within three weeks he’d calmed down, he’d bought himself a bike, he’d bought himself a rabbit and a hutch and some straw, things were okay. Still needing support and care, still needing guidance, he wanted to buy other things but they managed to persuade him that may not be the right thing to do. And six weeks later a very different man: very calm movements, better control, they were saying, “What a nice man; we don’t need to throw him out now, he’s okay”. So, there’s an example of with the right advice and approach the budget for social services is much less because they don’t now have to pay for a secure unit for him. He’s fixed by and large. It’s an on-going piece of work but I’ll keep an eye on that. So, sometimes when you’ve demonstrated… that goes a long way. If you can demonstrate a success story like that it spreads and you get asked to get involved in other cases. So, successfully managing somebody with HD is a bit like earning your wings and word spreads, “Oh, [Name of respondent] dealt with that one last time; why don’t you give her a ring?” That’s kind of helpful. But the issue remains for me that nobody really – very few people outside of our HD circles – knows what this condition is so they get in conflict with the police, they get in conflict with authority, all sorts of problems, and are not seen as nice people because they are untreated; very hard and very hard for the family to watch that, very hard to continue any kind of relationship with the family, children, so forth, if all that’s going on. So, there’s a lot of stuff that happens that I think doesn’t need to if you can get in early, which is where I come from. If they can come from the genetic diagnosis to our service if all I do is say, “This is my number; give me a ring if I can help with anything”, that’s the right time to step in; if we can produce a pathway for people to work through for GPs that would be helpful. “If you’ve got this presentation this is what you do.” We need to stop or we need to be informed, services need to be informed, or if they are not informed know who to call, and that’s very easily done. If I was a Nurse on a ward looking after somebody with cancer I would look for a cancer Nurse specialist to come and talk to us about what we needed to do, what we could help with, how to do dressings, that kind of stuff – it’s not my area of expertise – and we need other people to do the same with this: “Okay, we’ve got somebody here with Huntington’s Disease; we’re not really sure about this, let’s ask [Name of respondent] to pop over”. That message needs to be spread that if you can spread the word things can be easier.

[0:35:40]

Interviewer: So, I mean you have a great website. You’ve developed a pathway. So, I’m puzzled because if this chap was moved to his fifth nursing home I mean surely there was social care interaction throughout this and before he was admitted and all that, so I mean I’m assuming that there isn’t one Social Worker allocated, that these are just generic social care services, that you don’t have one person allocated to his case; but whoever picks up on this case now and then why don’t they go on the web and search? I mean what is blocking them? Is it because they think they know best?

Respondent: Sometimes, yeah; sometimes that is very evident. This particular case: he went around London a couple of times, he was moved around in the London area. It came down to [Location 2] – I don’t know why you move somebody from London to [Location 2] – but they moved him to a unit that was reportedly good at dealing with challenging behaviour – they’re not but that’s how it was sold. So, when he went to this home in [Location 2] and then carried on being aggressive and nasty they just wanted to give him notice and the social services were saying, “Okay, he’s done five homes now and none of them have worked; we’ve got to look for a secure unit”. And somebody at the home said, “There is an HD service; [Name of Respondent] used to come sometimes. I’ll give her a ring”. And I was told by an angry Social Worker that this person had been referred to us three times and we’d rejected the referral. I said, “Okay, I’ll challenge that now”. I’m old enough not to care what people think about what I say now so I said, “This person has never come to my attention because we would never have rejected that referral. I would have been out much sooner. This is word of mouth”. So, unfortunately he’s there for a long time hitting people; had I been informed a long time before we could’ve gone out sooner. But somebody at the home didn’t recognise that they have a service locally for people with HD, “Give [Name of Respondent] a ring”, but that actually never happened. And the Chinese whispers got back that we’d rejected the referral; not true at all, we’d never had one. So, I think again I think a lot of people might think that we know everybody with HD in the area; of course we don’t. We only know them if they are actually referred to the clinic. So, there might be hundreds of people in [Location 2] that I’ve never met and don’t know. So, unless they are referred to us we’ll never know about them. So, it’s very difficult trying to spread the word and widen things. But what I see now is people are learning from events. People are ringing me up and saying, “Oh, last time you did this; could do this again? Could you go and have a look at him?” and that’s a positive thing. The issue is what happens when I retire because at the moment you can’t do it all and I want to spread the word to primary care and mental health services so that I’m not needed, so that they go, “Oh yes, we’ve got a person with HD; this is what the pathway is”, and crack on with it. It’s not rocket science to do that at all.

Interviewer: So, what is the plan then for when you retire? So, you have two Consultants trained now, right? Or I mean I don’t know if they are Consultants but they are Doctors. There are monthly clinics and there’s the pathway so there’s the Genetics service, there’s the Neuropsychology. Is there a plan in terms of who will be the Huntington’s Disease expert?

[0:40:00]

Respondent: Not really, but there isn’t any plan to replace me. I mean I’m not going anywhere just yet, but in terms of succession planning we need to do that. And I’ve been told to write my own business case; well, I will if I’ve got five minutes to myself. One of these days I’ll write a business case. But it’s not even seen, I don’t thin, by the hospital that it’s a valuable service. Now I know that I’ve kept many people out of hospital, I know that I’ve kept people out of psychiatric care because we’ve got in quick, we’ve changed the medicine, and I know that things have happened because of our intervention. But proving that is a bit like not sniffing lavender to prove the effectiveness of aromatherapy; how do you prove that you’ve prevented stuff? So, how would a hospital Trust – and bearing in mind it’s an acute Trust, not a mental health Trust – see that as a relevant thing to fund? I personally think I should be funded by mental health services or half and half, so I think at some point somebody’s got to say, “We’ve got no more [Name of respondent] anymore so you deal with HD people all on your own. We’re not dealing with that”, because in crisis you’ve got somebody on your ward with HD who is very distressed: what good is an HD clinic appointment in six months’ time? None at all. So, the benefit of having me so that I can pop in and talk about it… And it just needs a Psychiatric Nurse who is not afraid of people who are maybe a bit irritable and might shout at you and that kind of thing is recognising that as a treatable condition. I’m very happy to train people up. And that is in conversation about getting other Nurses working with me so that at some point we can spread the word a little bit more, but I think before I retire I need to put a lot of stuff down on paper; I need to write a book, I need to write pathways for secondary care, I need to write pathways for GPs. And that can all be done; it just needs time which there isn’t a lot of.

Interviewer: Which you don’t have.

Respondent: Which I don’t have because I’m seeing patients; yeah.

Interviewer: Where is the closest specialist team for Huntington’s?

Respondent: London UCL.

Interviewer: It’s London?

Respondent: Yeah; then Oxford.

Interviewer: Yeah. And they have a whole shebang of Huntington’s, right?

Respondent: They do, yeah.

Interviewer: Do you think they wrote their business cases?

Respondent: They are a centre of excellence aren’t they so they were funded, but they don’t have a roaming person, they don’t have anyone that comes out of the clinic, and this is the issue for me. And it’s really, I think, easily solvable. If we had one person in each mental health team in each area who had a special interest in Huntington’s Disease we could train them all up, we could hold link meetings, we could do support, peer supervision, and they could deal with these issues under supervision. When I used to work in CMHTs before you’d have somebody who is really interested in alcohol-related problems, you’d have somebody who is really interested in schizophrenia, somebody who is really good on the therapy side of it, the cognitive therapy side of it; everybody had their own particular interest. I think if we got somebody in each mental health team interested in this that each team then would have a focus point, and I think things might be easier.

Interviewer: I like that idea to have a link worker or liaison or whatever it is.

Respondent: Yeah. The issue for me is that there’s already, as I said before, speech and language, Dieticians, Physios; they are already there and if you have somebody who needs those services it’s just a case of a referral, a phone call, and those services come in. The greater issue for me is how to manage these sometimes very difficult mood problems or anxiety problems or cognitive problems, and if you’ve got a service that would deal with them in anybody else but not in somebody with Huntington’s Disease that’s the issue that needs to be addressed more I think. And they’ve got a team in – every town has got a mental health team, why don’t we just train somebody in that team? It could be a Doctor, a Social Worker, a CPN, anybody who is interested. And this is becoming a little bit more apparent in [Location 2], that people are interested; train them up, spread the word.

[0:44:46]

Interviewer: So, when an HD patient now deals with the mental health community team I mean does it happen that they deal with the mental health community team, or it always goes to you?

Respondent: It depends. If they know us it’ll come to us; they’ll call me or the GP might get in touch with me. But some do go straight to the mental health, usually in crisis, and that’s when mental health will say, “We’ve got one of yours in our admission unit; they’re in crisis”, they PPA. So, yeah, that’s usually when it comes to our attention because they’ll have them in their unit; they’ll give them all the wrong medications and there’s no progress and they’re still there six months later, then they’ll call me. It’s variable but I’ve had some successes recently. So, as word spreads it’s worth waiting for that to happen. I keep saying to mental health units, “You’ve had somebody on your wards who was a bit of a nightmare; now much improved, now can go back into the community and live a much better quality of life; well done you. Please write this up: how you dealt with it, what your conclusions were, what treatment you used”; nobody ever does. I keep saying to people, “Please write it up; spread the word”.

Interviewer: So, [Name of Respondent], do you think it would be helpful if social care also had a link for Huntington’s there?

Respondent: Yeah.

Interviewer: I’m asking because I get a lot of complaints from Social Workers not knowing and doing more damage than good. It will go out public but sort of like they almost rather people are not being involved. If they knew what would happen they would rather not have them involved, which is quite bad.

Respondent: Yeah. There’s a mental health team in every town; there’s usually a mental health Social Worker in every town too who has got a particular interest in mental health issues. Or the physical disabilities teams; if you can get into them, and I’ve got into some of them that works well because they’ll ring me when something crops up and we can have a chat on the phone and they’ll say, “Okay, I’ll go off and do that then”. And it works when you’ve got a tried and tested case already under your belt; it helps. So, I think with how these services integrate: they are already integrating but they don’t know what they need to do next. So, Physios talk to OTs, talk to Dieticians, talk to Gastrology for peg feeds, they talk to Social Workers, but they don’t come to us. And I need to be part of that circle so that we can train each other up, we can spread the word. Maybe my job sits in the wrong hospital; I think it ought to sit in the mental health unit maybe or half of it in mental health to make it that much more obvious. Yeah.

Interviewer: Okay. So, I get from the conversation that it’s much more that Neurology apparently versus Mental Health than Health versus Social Care?

Respondent: Yeah.

Interviewer: Okay.

Respondent: And that’s not new in this country the battle between Neurology and Mental Health. Neurology and Psychiatry used to be the same thing and it parted. The passing of the disciplines: people became a Psychiatrist or a Neurologist. So, they were all one and when I started training Mental health expected to take people with these types of conditions because they thought, “Well, these behaviours are what we do”. And in recent years it’s got very much more split. If you talk to people like [name redacted], who is a Psychiatrist, he’ll say, “We used to do this routinely; we would have people admitted who had Huntington’s Disease and we would see that as something that we should get on with”. Something went wrong in the Care in the Community Act really which emptied hospitals of people with long-term mental health problems, and I think that had a significant impact on how you manage people. So, the argument between Neurology and Psychiatry is not new; not new at all.

[0:49:30]

Interviewer: Do you think something happened that actually increased the stigma of mental health conditions? As you are saying, were they more present in the acute care than they are now?

Respondent: Yeah, I think so. I’m old enough to have worked in the system where there were long-stay beds in mental health units; they’ve all gone now. But that would’ve been where somebody maybe with Huntington’s Disease or schizophrenia who had these challenging behaviours and very difficult cognitive function and mood would be looked after very well in the institution. Now people knock an institution but actually I worked with people who were very caring, very compassionate, and very keen to do the right thing. Okay, the buildings weren’t good but the commitment and the expertise was second to none in a lot of places where people did their very best to try and get on top of people’s symptoms because that’s what your job was in a long-term setting. So, when the Care in the Community Act kind of said, “Actually all these people with long-term problems, schizophrenia and so forth, they don’t need to be in hospital; they just need to be cared for in the community”, so the money was devolved to social services and primary care to look after people who were way more intense in their needs than people assumed. I think people assume – a bit like dementia – you go to some homes and it’s warehouses really where those needs are a person is fed, they are put to bed, they got out the bath; that’s seen as an acceptable level of care, not to me it isn’t. But if you’re thinking about, “Okay, who pays for this?” that person just needs to be fed and all their needs met but they are not a challenge in any way so that’s for Social Services to deal with; there’s sometimes not a lot skill or knowledge. The more complex ones who have health needs are funded slightly differently but they are still in the same care homes. So, they all went into the community, the long-stay beds in hospitals were all closed, and that’s part of the problem is that these people are living in care homes or in their own communities, there is no bed to admit them to, the bed numbers have dropped dramatically in mental health. And so the ones that you have the staff that you have left are very focussed on Psychiatry – this is organic Psychiatry and there’s not so much interest in that. So, I find people with HD in geriatric nursing homes being very distressed, and no expertise to look after them which is very sad; when you’re looked after by Psychiatric Nurses and Psychiatrists and Social Workers and OTs who deal with that it’s a very different story. Sorry I interrupted you.

Interviewer: No. You said there you also do training in nursing hommes or you also do go into nursing homes? Did you say you do training?

Respondent: Yeah, I do a lot of training; I do a great deal of that. Care homes: if they’ve got somebody with HD they kind of seek training and I’ll do that a lot. I’ve done a lot of work with one care home where they’ve now got eight people with HD and a lot of training with staff has worked really well. And their call-out rates have dropped, their incidences have dropped, their drug budget has dropped, because they’ve been able to be trained and we share all those experiences; that’s worked very well. I train Social Workers quite a bit. I’ll often go into GP surgeries. If they’ve got somebody in their sights who is maybe a bit of a problem then they’ll ask for help and that kind of spreads the word. Yeah, I do a lot of training.

Interviewer: Okay, that’s good. I mean even if there is some rotation of staff in the nursing homes because the staff are properly trained and they sort of also train each other I guess they get into that right mind-set and they know who to call should the situation –

Respondent: Yeah.

[0:54:03]

Interviewer: Yeah, okay; alright. So, [Name of respondent], if there was something that could do than this better balance between Neuro and Psychiatry or between Health and Social Care or having people with complex needs in settings where the level of care is just not… there’s a complete mismatch what do you think would change at a person level in terms of what difference would it make for the patient or for the families? What would you see or what do you see? Once you intervene what do you see changing?

Respondent: I think it’s a bit like… young-onset dementia has the same problem: nobody really knows what to do with somebody who is 50 who has got Alzheimer’s disease because services are geared for 65 and over or under-65. So, there are plenty of services for people with physical disabilities, there are services for people with mental health problems, but they’re not all connected and I think that’s exactly what you need when you’re dealing with somebody with a neuro-degenerative condition. So, I would like to see a very clear pathway for anyone to look up and say, “Okay, I’ve got this diagnosis; where do I go now?” It should be that crystal clear that, “This is what happens”. What we can’t really plug at the moment is, “Well, you can have [Name of Respondent] come and see you”, because I can’t do everybody and, as you’re saying, if I’m leaving in [couple of years time] what’s the point because the ability to be mobile is crucial to this. If people aren’t expected to come to the hospital the hospital comes to them. So, it’s a shift in thinking; it’s a shift in budgets; it’s a shift in traditional thinking; and it’s having more people like myself to access the Neurologist as needed, to access the GPs and needed. It needs to be seen as quite important. And I think if you have these high-intensity highly complex patients that nobody really understands the illness that’s fine; if you don’t understand HD that’s absolutely fine, there’s lots of stuff I don’t know about other conditions but I know who to ring if I need to; that’s what needs to be sorted out I think: a very clear pathway for everybody to know. And maybe it’s just embellishing what we’ve already done. But then in order to do that then we need to say, “We’ve got three Nurses; one of them will come out and see you; one of them will advise you, can you can access our nursing staff”. I can’t do that at the moment because we have limited resources. We could set up pathways with GPs so that they record people who are at risk, they are alerted; that’s not rocket science at all.

Interviewer: Yeah; that’s why I was asking. I’m a bit like, “Why is it not there?”

Respondent: Well, that happens with young-onset dementia for example and often not recorded on a GP database because people think that’s a stigma, “We don’t want to label somebody who is 55 as having dementia”. So, if you try and count the number of people in primary care who have younger-onset dementia you’ll get a very low number; it’s not the real number but they are recorded differently. This has been an issue for younger-onset dementia for a long time. And if you go to a GP, “How many people have you got on your list with young-onset dementia?” “Oh, three.” “Really? I don’t think so”. But how it’s recorded is important. So, I suppose what I’m saying is a lot of the services are already there; it’s about how you integrate that and set the pathways for all of us to make it very easy to deal with somebody who has got HD or schizophrenia or Parkinson’s Disease or multiple sclerosis; it should be very straightforward and I don’t know why it isn’t.

Interviewer: So, if we had this what difference do you think it would make at the patient level or at the family level?

Respondent: Well, patients say to me, “I said to the Doctor I had Huntington’s Disease and he said, ‘What’s that?’”. People get very angry with GPs who say, “Oh, yeah, what’s that? I’ve never heard of it”, and start typing. And this irritates people, understandably. There should be something crystal clear: “This is your area; you live in [Location 2], this is what you do”. And I think the patient should be able to access that so that they know so that they can go to a GP fore-armed. They should know what the services are; it should be very clear what the services are. And at the moment they are all there, they’re just in bits all over the place and not properly funded. I think if a patient knew, “Okay, if I get problems that’s the route I go down”, well I think that’s what I would want. And I think GPs want it and I think Social Workers want the same thing: a very clear pathway that has very clear communication routes within it. But it needs resourcing; it does need resourcing.

[0:59:45]

Interviewer: Has this been taken to… I mean before it was the CCGs or something and now it’s the ICSs, the money, the budget.

Respondent: I’m a bit detached from that. I mean the sort of work that we do is being noted because it’s saving people money, it’s saving distress, we’re managing people quite well in the community. But I’m a bit divorced from that. I don’t know what the ICB think really; that’s more of a question for [Name 1] really. I’m not part of those conversations but it has to change because I remember when I first started – I may have told you this story – when I first started in this role somebody quite senior in the Health world said… I said, “I’m younger-onset dementia and Huntington’s Disease”, and they said, “Huntington’s Disease: is that really worth your time because what are there in [Location 2], how many in this area? Five, six, eight, ten; not many”. And the answer to that is, “There may be fewer in numbers but they will take up every penny of your resources; they’ll use all of your time, all of your budget, if you don’t get it right. So, that’s where the money hurts. You can put somebody with HD in a specialist forensic secure unit which will cost you £4,000 a week or you can give them an anti-depressant and none of that will be necessary, which costs about £1. Do you see what I’m saying? Money is leaching out of the NHS and the Social Services are spending the money in the wrong places. I could save money and fund myself.

Interviewer: Yeah. I mean the fact that you exist and, as you are saying, for example London has a big team but they don’t do outpatient visits or community visits; what’s the feedback you get from people when you’re available, when you pick up the phone, when they actually know who to ring?

Respondent: When they get in touch with me?

Interviewer: Yeah. No, the fact that they know you exist; what’s the sense you get by the fact that you have this role and they have your number, they have your card?

Respondent: Well, I hope they feel reassured by it and they know that they can ring or drop me an email and we’ll take it from there. I always say to people, “I don’t know what I can do for you but you’re now in the system and if you’re fine for the next two years brilliant, but if you’ve got a question…” I’d rather they wrote to me and said, “This happened to Dad yesterday; is this anything to worry about?” I can have a think and say, “Maybe talk to the GP about that”, or, “Should I pop out next week?” That’s how it works and that works, and people say they feel reassured, they know they can ring, they know they can send me an email, they know they can ask a question. And I think that’s based on my initial work when I came into post about what people wanted. And Clinicians wanted access to specialist advice; they wanted to know where to go. Patients and families wanted the same thing; they wanted to know who to ask a question of. In those days we were seeing people perhaps every year or every 15 months but where do they go in-between times with a question? They’ve got somewhere to dump it now and maybe I can act on it. So, the feedback is that they appreciate it. And I’ve been to things like at the HDA and people have said, “Oh, what do you do?” and I’ve said, “Oh, I visit people at home”, and, “What? You go and see them at home?” It’s worth a fortune, it really is, and it’s a very simple intervention really. People appreciate it.

Interviewer: HD godmother showing up.

Respondent: Fairy; “Here she comes on her broomstick”, yeah.

Interviewer: Well, you may sound like a witch now; no, godmother is much nicer. Okay, good; alright. So, now I’m going to do a bit of boring questions that we need to tick. How old are you, [Name of Respondent]?

[redacted]

Interviewer: [redacted] Okay, is there anything you would like to add to the interview that we haven’t covered?

Respondent: I don’t think so. I can blow our own trumpet and say we do a really good job in [Location 2]; that’s for other people to judge. But I think what we do is loads better than nothing, and I think having a foot in Neurology and Psychiatry would be even more helpful. And I don’t think it’s that difficult to solve but it needs lateral thinking. Like I said, all of these services already exist in every town so why are we just not joined up? I don’t know. The difficulties in Huntington’s Disease such as the career are not the main issue; it’s mostly the mental state and the cognitive changes that cause so many of the problems in HD. It would be lovely if we could just be part of a bigger team, not just me driving around on my own, that linked in and that everybody could share in. That would be exactly what you’re looking at: how do you integrate services so that they work easily for the patient. I don’t think the patient should have to work out who they’ve got to phone, which is why say, “Phone me and I’ll try and work it out for you”. They are already dealing with great difficulty, why are we making it so much more difficult for them to negotiate and navigate their own care? The Care Navigator role that this was kind of modelled on is helpful, so that’s very prominent in the states and that’s mainly with cancer care you get a Care Navigator who will help you negotiate all of this kind of stuff; that would be helpful in this system too. So, you get allocated a person.

Interviewer: I saw some webinars about… I don’t know if they were called Link Workers or Social Prescribers or something like that and I said, “I’ve never had a patient that ever told me that they had been in contact with a Social Prescriber; where are they? What is it that they do?” I mean is that a role you’ve had any contact with?

Respondent: Yeah. There are Social Prescribers sit in GP surgeries in primary care and I have to say the ones that I’ve come into contact with have been really quite helpful because they are looking at what that person might benefit from that’s available in the community. Now I don’t know everything about everything so I’ll always say to people, “Go to Citizen’s Advice; they will advise you about benefits, finances, all that kind of stuff”, it’s not my area of expertise because it changes all the time. And if there is a Social Prescriber they will know all the day centres, clubs, voluntary work, those kinds of things, classes, free gym membership, that kind of stuff that might be helpful. So, if they do exist I do say to people, “Go and see them”. I have a chap with HD who has significant mental health problems; we calmed those down a bit but he was very bored at home and up to mischief. The Social Prescriber got him into voluntary work in coppicing in a local forest and helping with boat building and things like that and he was in his element. He really changed because he had stuff to do, he had some responsibility, he was well-supported, and that really helped. He had a little job, voluntary work; she got him free gym membership so he can go to certain classes twice a week. All of that kind of stuff is really helpful.

[1:09:41]

Interviewer: Yeah, keeping a healthy lifestyle; okay.

Respondent: Absolutely; really helpful.

Interviewer: They just need to well enough to take part.

Respondent: Yeah, a time and a place; yeah, absolutely.

Interviewer: Yeah, okay. And we didn’t quite speak much about how do you link with the voluntary sector. [redacted] Are you still very in touch with a charity, with a Huntington’s Disease charity?

Respondent: [redacted] I’ve pointed people in the right direction but I’ve not flogged it because they kind of were very clear that they were short of staff and running out of money, so what the HDA Advisors could do was perhaps a little less than they used to do before. They are good people who mean well but there are not enough of them either. So, I tend to go off and do my thing, which is a bit more clinical; that’s my focus really: getting people the right treatment and the right support, and that might be referring them to [Name 2] but beyond that what she does then is up to her. I think there’s not the cohesion that there used to be, yeah.

Interviewer: Yeah, okay. And with [eHealth app] I mean people can send messages and stuff but it still goes to you either way? There’s no one else picking up on any of that?

Respondent: No, it’s only me. We don’t get a lot through [eHealth app] because people have already got my email and phone number so they just ring me, so they don’t need to go through that system which is my fault. I should give out the [eHealth app] message board.

Interviewer: But then you have to work to set them up and it comes to you either way so…

Respondent: Yeah. So, there’s not a great deal of input in [eHealth app] I have to say. We do register a lot of people but whether they use it or not is very debateable.

Interviewer: You don’t know if they do like if they want to see a private Neurologist or something? I don’t know if you get any feedback of people using the system, because they get their letters and medical tests?

Respondent: They can but so many people get signed up to [eHealth app] and they can see the letter that [Name 1] has written for example, but there’s nothing else for them to see because my letters don’t go on there. So, yeah, that’s another IT issue. They can send a message but they tend not to because I’m saying, “Call me; just send me a message, just text me”, so why would you feed them through a different system? And it went through a phase of people said, “Well, I did that but nobody ever got back to me”, and the messages were going to somebody who had left – I don’t know who that person was but others get hold of the systems and mess it up – so I’ve always said to people, “Just drop me an email”, it works that way. So, it’s not maybe very good for people who have come into problems.

[1:13:48]

Interviewer: Because when they lose capacity what happens to their account.

Respondent: Absolutely.

Interviewer: I was never quite sure about that part.

Respondent: No, neither am I. I’m not sure.

Interviewer: Okay; anything else [Name of Respondent]?

Respondent: I don’t think so. We need more money; that’s all really.

Interviewer: “We need more [Name of Respondent]’s; we need more money.”

Respondent: More hours in the day.

[redacted]

[End of Transcript]