

Chapter 2: An Impossible Tightrope

Hattie

Yep, it's definitely recording.

Helen

Mine's recording too.

Yeah, it's weird. You want to almost try and forget that you're recording yourself, but then on the other hand you want to maintain that degree of, not like self-consciousness, but it's like Eve said, like going through and making it transparent and sort of talking through the process.

Hattie

I have to forget that it's recording because otherwise I feel too awkward, because I hate how my voice sounds on recording and I never realise how weird I sound! [laughs]

Also I've got a cup of tea right, and these microphones are intimidatingly good. So there's gonna be such loud gulps all the way through [laughs] it'll just be in the transcript in square brackets – big slurp! [Helen laughs]

So you were saying about talking, jumping back in with talking a bit about insight and what that means to us. I don't know if there was anything that you wanted to start off saying about that Helen?

Helen

It's a word that gets used a lot. Like, a lot. I'm sure you know yourself.

People are described as *having insight* or *lacking insight*. And I've been told almost all the time how I have such fantastic insight. You know, they say it as if it's an advantage, "Oh you've got such great insight". You know, it's such a good advantage, having the knowledge, having the insight, is the first step. It's 50% of the challenge, having the insight. So you think, "Great! I've got this insight. And they think it's good."

But then you discover that it gets used against you because there are expectations that professionals have of you when they consider you to have insight, whatever that means, because what does that actually mean, you know?

So I think there are expectations that come with it. That if you have insight you should, I don't know, not that it's easier for you, but, you know people always say, "Oh you're intelligent" or etc. and you almost feel as if they

expect you to logic your way into getting better, when often it doesn't always work like that.

I don't know about you, but I often find I've got very good theoretical knowledge, technically I've got insight because I can sit there and recite all the facts and stuff, but then I think when it comes to actually applying it to myself, that's where I have a lot more trouble. And that links in with this concept of capacity, but I'll get into that a bit later.

I don't know, I mean, what have your experiences been in your care with this idea of insight?

Hattie

Yeah I really feel you when you say, "What does it actually mean?" Because I feel it's a word that's used a lot but often without a clear agreed consensus on what the definition is. And it's sort of thrown around a little bit.

Yeah I've certainly had experiences where I've been told, "Oh, you've got good insight." And I'm sat there in the plastic chair twiddling my thumbs thinking I don't know how to respond to that. Like, thank you? Yeah, I know, obviously, I live with my brain all the time! Like, I don't really know what is meant by it.

I remember when I was first diagnosed with some of the illnesses that I've been diagnosed with, I did a lot of research and I bought medical textbooks in charity shops and would read through those.

But I think that one of the things about when professionals say, "Oh, you've got good insight", I think what they're saying is you understand your experiences in a way that they agree with. Rather than the times where they say, "Oh, you don't have insight" is because you have a different idea to them about what your experience is.

And in terms of defining insight as saying it's how you understand your experiences, I feel that I have been able to do that so much better, and in that sense I have better insight, as I've been able to move away from other people's definitions and move towards defining my experiences for myself and working it out for myself, rather than going on labels that have been prescribed to me by other people.

I think I strongly feel that it's a lot about how your understanding of yourself is aligned with the professionals' understanding.

Helen

I totally agree.

And it just reminds me of an example from my Trust, where recently, in my data mining attempts, tried to find more information about the services. And I was on the Clinical Commissioning Group website and I found a document outlining this proposal for something called a Sustainability and Transformation Partnership, some way in which they're transforming the services.

And it was all about how they're going to transform the eating disorder service. And I read through it and there was a tiny section, you know, compared to the rest of it, about addressing inequalities.

And I mean, it was very vague and it didn't mention being autistic, it didn't mention autism at all despite the fact there is quite a significant comorbidity between autism and eating disorders. And there was one line, it said, "Black, Asian, Middle Eastern people, there may be a higher incidence of eating disorders but they may not explain their symptoms in a biomedical way, which is why we don't pick up on it".

And I was like, well actually, it's not on them to explain their symptoms to you in a biomedical way. You know they always talk about us reaching out, and it's like, well why don't you actually reach in and try and make more of an effort?

You know you've got to consider privilege as well. And sort of how you've got to describe things in their terms. It's got to align with how they view it to sort of, not they look upon you more favourably but, I don't know how to put it into words, but I know exactly what you mean. It's very much dependent on how do you fit into their existing parameters, rather than them trying to be a bit more imaginative. And yeah I've definitely found there have been times when I've disagreed with decisions and been told, or it's kind of been implied, that I don't know what's good for me.

I had a meeting, just yesterday actually, and I was saying, "Look, you've put me on this treatment pathway, which is inappropriate because these are the criteria, I don't meet them." And, you know, I'd been saying for ages that it wasn't going to help.

And she said yesterday, she said, "Helen, we thought we were trying to help you". And I was like, "Well, you could have listened to me right from the start, but you just decided that I didn't know what was best for me."

You have insight when it's convenient for them, but when it doesn't fit in to what they want you to say they sort of, it's like they've almost got this script in their head where they expect us to stick to that. And if we diverge from that, and if we don't do what they want us to do, they don't know how to respond. And they become, in my experience, they become very defensive.

Again capacity is one of those words, you know, *has capacity, lacks capacity*, what does that actually mean? Because capacity is actually something that is context specific. When you assess if someone's got capacity it's only about can they make this decision at this particular time when they need to make it. So you can't really make a blanket statement.

There's a distinction between knowing stuff theoretically, but actually being able to apply it to yourself. I know I've been in situations where I've taken pretty big risks to be honest. And I sort of knew theoretically what I was doing, and I would almost sort of research what I was doing, but I think I never quite understood. I kind of thought nothing would happen to me. I assumed that if I planned it enough, if I just had enough knowledge that would somehow protect me.

And I remember speaking to one of the staff members about it and she was like, "Helen, I don't know why they haven't been doing, you know, I think they should be doing proper capacity assessments actually every time you presented at A&E, because you know the risks in an intellectual sense but you weren't able to act on that to make the decision to do X or Y."

Have you ever had similar experiences with that concept of capacity? Or has it ever come up for you?

Hattie

Again, as you say, it's a word where it's thrown around and is often used maybe where it's not the appropriate word.

So I've had experiences on either end of the spectrum of being, you know, detained under the Mental Health Act, and the Mental Capacity Act as well, where I've been deemed to legally not have capacity to make the decisions, and then also times where people have said, "Oh, you have capacity so, it's not our problem if you go and do this". It's the opposite ends of the spectrum, but both have been pretty painful experiences.

There have been times where I was sectioned or the Mental Capacity Act had to be used and that was absolutely necessary and saved my life, but the actual treatment of that is a bit of a different story.

But there has been other times where I've been in hospital and I've been in a crisis and it's sort of been the phrase, "Well you have capacity, so X, Y and Z." It's been used to justify denying me care, to justify not providing further medical treatment, to discharge me or to justify not meeting the needs that I had at the time.

Yeah and I guess that does tie in quite closely with insight. And I suppose there's been a lot of times where I've been told, "You've got really good insight" blah blah blah. But also times where it's sort of been said that I don't.

And I think, just going back to what you said about what was on your Trust's website, like I think it's so often about, it's not that I, in these times where it was said that I didn't have insight, it's not that I didn't understand, it's just that I wasn't communicating it in a way that they were open to understanding.

I understood my experiences in a way that didn't fit in with what they'd learnt in the textbooks. But that doesn't necessarily have that much reflection on actually the experiences that I was having.

It just was that they weren't open to hearing things in a different way.

Helen

I've definitely experienced this ever since I started to challenge them.

And then particularly since they discovered I'm autistic, and that kind of works against me even more in a way because the way that I communicate is maybe a bit, not different, but for me, you know, that's shaped the way that I understand my experiences now.

And I think what they're struggling with is they've got this formulation that they made for me 18 months ago, which, you know, it's still valid, it's still kind of accurate, but obviously the autism diagnosis kind of massively, I see my experiences in a bit of a new light now.

And I keep trying to bring this up, and I keep trying to say, well, you know, I think we should go over that formulation again, in light of this. And they sort of, they're quite resistant.

And they keep sort of saying, "Oh, well, from your formulation, I can see X, Y and Z". They're unwilling to take new information and insert it into the formulation, and they're unwilling to understand my perspective can change.

Hattie

Yeah things change in your understanding and how you view things is fluid anyway.

But choosing to ignore such a significant thing about you, both the experience of being autistic in itself, and then also the difficulties you've had being autistic in a world that's very much not designed for neurodiverse people.

Like, that's such a huge part of your experiences, and just sort of choosing to ignore that, for whatever reasons, the convenience of not updating their understanding maybe, is just, like, looking at half the picture. It's not serving anyone.

Helen

Exactly!

And I try to help them, you know because ultimately it's just about getting them to improve. But they're sort of very, "This is the way we've always done things and it works for these people, so why doesn't it work for you?"

And it's funny because I'm the one that they say is black and white and is rigid. But they're also the ones who are actually unwilling to change their minds and unwilling to take in new information.

And I just find it kind of funny. Because I've been trying to not mask as much, I've been trying to communicate in the way that I want to, I think they find it quite unnerving, almost.

Like I had this meeting recently and my dad was like, "Oh, you didn't mince your words!" I think I used to take a more conciliatory approach, I used to be like, I have to be good, I have to say what they want me to say, but now because I'm trying to be more direct and assertive, and it's funny because they were the ones who told me that I had to be more assertive.

But now when I am assertive they don't like it!

Hattie

Yeah, now you're being *difficult*. Be assertive, but not *too* assertive.

And tell us what you need, but also shut up! [laughs]

Helen

Oh I know! You feel like you're walking this impossible tightrope where you can't reach out for help because you're seen as care seeking, you can't not reach out for help because then you're just seen as not engaging or resistant.

Like you said, you can't have too much insight otherwise you're trying to question everything. You can't have too little insight. Well I say insight and I'm aware that I'm using that term there when I said myself, what does it actually mean?

So you feel like whatever you do, you're sort of damned if you do and damned if you don't. For me, it makes me feel very very trapped. Like they said to me, I've been placed on this care pathway and they said to me, "We're not forcing you Helen, it's your choice." But actually there's not really another option.

And I was like, "Well technically, you're not really giving me a choice." [laughs] And it just got to the point where I was just gonna do what they say.

Hattie

Yeah I think you have to learn how to perform in the way that works. Because at the end of the day, you need to have your needs met. And with services working in such convoluted and strange ways sometimes it can be not always very simple to get what you know that you need.

One of the experiences I've had that's really stuck with me, for quite a few months I was in hospital, so I'd been on an acute ward and then I was transferred to a private but NHS funded ward, and it was for *women with personality disorders* – all of those words in air quotes [laughs]. And it was such a toxic environment. And it was so hard trying to heal in an environment and a system that so strongly reinforced the things I was trying to heal from.

You know, the staff were so stretched there was never time for the patients. So they would always say, "You need to come and talk to us if you're feeling unsafe", or "You need to come and talk to us before you do something." But then you would do that, and there wouldn't be any staff because they'd be all caught up dealing with an incident somewhere with somebody else.

And so you'd be sat there knowing that you've been told 1000 times it's your responsibility to go and reach out and to speak to somebody, but there's nobody there. But you know, because you've seen it, that if you were to do X, Y and Z, then suddenly the alarms would be pulled, everyone would be there, you'd then be put on 2:1, you'd have people there all of the time. But then you get told that you're attention seeking and that you need to be taking more responsibility.

But how do you do that in a system where your needs aren't met when you seek those things in a safer way?

