

## Chapter 13: A Low Priority

### Shan

When I use the word insight, not necessarily about others, but when I'm talking about myself having insight, what I mean is that I'm able to see things from multiple perspectives simultaneously. I don't know whether it's because I identify as multiple, or because my studies are rooted in anthropological disciplines. But when I say I have insight I'm able to step outside of myself, but be inside of myself simultaneously.

So I mentioned Alex, to Eve, a bit earlier before this meeting, that I'm actually mid-crisis at the moment. So when I say I have insight, I'm able to be like, "OK, aaaaahhhhhh", you know, "This is all going on for me, and aaaaahhhhhh, and that's what's happening inside". But at the same time I'm able to step outside my body and be like, "OK, this isn't how you usually are. This is a crisis. Maybe you should think about phoning a friend, phoning the crisis line so they can tell you to have a hot shower, which is like useful as fuck, but there you go".

And so I'm able to see things from these multiple perspectives simultaneously. So what I'm talking about, that kind of insight, gets me into trouble in the services. Because they're like, "Oh, well, she understands that these are the voices and that they're not real." You know, "She knows that people aren't trying to kill her", for example, "She knows that that's not actually the case". But I'm like, "Yeah well I know that, but I don't *believe* that" is the problem. See, there's believing and there's knowing. And the two don't line up for me.

So it's kind of like how I believe God exists but I acknowledge that for other people God doesn't exist, and I can totally understand that atheism is in many ways the logical default position. But for me, that's not my belief and that's not where I'm coming from.

It's kind of like that being able to see multiple perspectives at the same time, but the problem is within services they're like, "Oh, she knows that these are voices and that it's not the truth, therefore we don't have to deal with her, she can be low priority in our caseload because she has this insight."

So I tend to be low priority in my hospital for everything. And, you know, like I said earlier, I am on the fortunate side of the postcode lottery. So I really do want to acknowledge that in many ways, I have been very privileged because of where I live in London. And, you know, there's huge diversity of services within London, and disparities within them.

But at the same time I do feel that I'm marginalised within my hospital, because I can talk to clinicians on their level using their language and be like, "Oh well this is what I'm feeling, but I know this is a voice." And they're like, "Oh well, then it can't be that distressing if she knows that." And I'm like, "No this is effing distressing [hits table for emphasis], you listen to me right now [hits table for emphasis], you deal with it [hits table for emphasis], you see me [hits table for emphasis], you arrange an emergency appointment, or emergency med review, or you give me diazepam, or, you know, whatever it is". Sorry I'm going off on a rant now but it just really makes me very angry. It really makes me really angry.

### **Alex**

No no it's OK. There's something Eve said that I really really wanted to flag up. Partly an issue of insight is, with my last psychologist I actually knew every exercise she was going to recommend me. I already knew about it. I had four sessions with her and then I was meant to have more, and then I was like, "This is completely unhelpful for me, I've been on Tumblr." [laughs]

The thing that made me remember, Shan, was you saying hot showers. Like, "I'm ringing you because I know all these things and I know none of them are gonna help me right now." I find it really hard. With that psychologist I told her, "I know this, I could get it from a textbook. I've got books on this." She didn't cancel the sessions of her own accord, which I found weirdly offensive. Because it's like, surely can you recognise that this isn't gonna help me? This is quite belittling.

So yeah, they always want you to take responsibility. And then you have this responsibility, and you have this awareness. And then they're like, "Good for you! I'm going to tell you how to tie your shoelaces again", or, "I'm going to tell you how to suck eggs". "I'm going to teach you to suck the egg of self-care". Sorry [laughs] I've gone insane because we've been talking so long!

### **Eve**

I think it's really interesting what you're both talking about in terms of definitions of insight. Because I've spoken to, oh my gosh I've lost count now of the number of people I've had these chats with over the past two and a half years, and each person I talked to has a different definition of insight.

### **Alex**

It feels like people throw these terms around without actually knowing themselves. It's right that you asked us what we thought about it. I found what you said Shan really interesting about, yours was about seeing from

multiple perspectives. And that was quite innately related to what you've got going on, as in being a system.

### **Shan**

Yeah I'm not sure if it's to do with being a system, or whether it's just because of my brain is kind of very anthropologically minded because I'm doing anthropology of music.

### **Alex**

I mean all of us are, like our ways of describing stuff are innately linked to our own experience right? So I think it tracks. And to be honest I think mine was related to interests I have in social sciences as well. Which I feel is a key part of me as a human being really, and my sense of self.

### **Eve**

There's so much going through my mind right now. I feel like the deeper you go in, the deeper the tunnel gets. I've spoken to some people during the research phase of the project who described insight as memory. I've spoken to some people who described insight as emotion. I've been talking to some people who've described insight as more of an embodied, physical experience of truthfulness, but that doesn't necessarily translate to a cognitive process. I spoke to one person who talked to me about insight feeling like a violation. They'd experienced insight as a form of violence against them, because they didn't feel ready and prepared and armed for what that insight was going to do to them.

### **Alex**

Yeah, no, I understand that. Sometimes I felt worried about to look at my records, like what's so-and-so gonna say about me? What have I apparently done? Are they going to say something that's going to be completely off base about me? Or do I have to confront this or that or whatever.

And once I'd flagged that I'd like, it's around that time around like 2013, 2014, around when we started, so this might be upsetting, it was around when we sort of started socially reckoning with like, well what is abuse? Like, it's not as clear-cut as we all thought. There's all these grey areas. And it's more about harm than about the actual act itself. Or like about what the victim feels afterwards than the actual intention.

All these conversations were happening and I disclosed to my psychologist at the time, no my psychiatrist, that I'd had an abusive relationship and I'd been groomed. And then he was like, "Well, we're going to have to deal with that and we're gonna have to talk about that." And I spoke about what happened, and he was like "No that doesn't count" effectively.

And then I spoke about it with counsellors since, and specifically counsellors who specialise in this, although that wasn't why I was going to see them, and they said, "No you're definitely right, your instincts are right." Spoken to people who have just vindicated me.

But I mean, the insight into what people think about you, I know this might not necessarily be what that person spoke about Eve, but yeah, that element of it can be very troubling.

**Eve**

That sounds like a really disturbing experience, to have been told something doesn't count.

**Shan**

That's hugely traumatic in itself.

**Alex**

Yeah it's traumatic because it's like, not to get too much into it, but I think what a lot of what the psychiatrist raised as reasons he didn't feel that it was such were deliberate on the part of the person who did it, you know? Sorry I'm about to go down quite a rabbit hole so I'm going to pull back from that because I'll sort of like upset myself if I do that.

It's an enormously complicated subject in so many different ways. And it's great to have the chance to actually talk about in this context. I've found it really engaging to think about all these experiences in a particular light, and a particular concept in mind, rather than just sort of feeling quite frustrated by my experiences as a whole and not really getting to the root of them from any particular perspective if that makes sense?

**Shan**

Yeah I mean, I just wanted to say briefly, you mentioned that one person felt it as a bodily thing, insight. And I wouldn't say it's quite a bodily thing for me, but I guess because I believe in souls, for me it kind of takes on that kind of supernatural sense of this is my truth. And this is my being. And if you're saying something that contradicts that, you're violating my truth. So it is kind of held in the body, but it's not a bodily sensation. For me a lot of people are like to me, "Well you have insight, therefore, you can't be psychotic, or you can't be *that* psychotic". And I'm like, "Well, what does *that* psychotic mean?"

You know, I think I was actually the first one to use the word psychotic about myself. And it was only after six, maybe six and a half years in services, the psychologist said to me, what do you actually mean? And I was like, "What do you mean?" She was like, "What do you mean when you say you're

psychotic?” And I was like, “That’s really shit deep!” [laughs] I was like, “What kind of question is that?” So I had to think for quite a good kind of minute of silence.

And then what I said to her, so for context Alex, without wanting to trigger anything for you, I've also had a kind of mild grooming experience at university and that's when my voices kind of changed. So what I said to this psychologist was, “When I say I'm psychotic, what I mean is I'm back at Oxford, which is where I did my undergrad”. And she was like, “Well, that's not really psychosis is it?” And I was like, “Yeah, but no one ever bothered telling me that before”. No one actually bothered asking me what I meant, or why I was using these words.

You know, I was using these words because I thought people wanted me to use these words. And because people weren't listening to what I was trying to say to them about my experiences at Oxford, so it was just easier to use words like voices, paranoia, people trying to kill me, than by like, “Oh well there was this thing and it wasn't exactly grooming, but it kind of was grooming.” It's kind of ended up like that. But I was like, “OK maybe I'm not psychotic, then”.

But then I went to my psychiatrist and was like, “Do you want to diagnose me with CPTSD?” and she was like, “No”. And I was like, “Oh, OK then”. And I was like, “I'm confused now, but whatever.” [laughs] I don't think they know what they mean when they say psychosis sometimes. I mean, I like it as a convenient shorthand so that I don't have to explain my life story to people. So that's why I use it. But I don't know whether I'm what I'm saying matches with what psychiatry is actually saying or who said what first kind of thing.

### **Alex**

Psychiatrists act like it's a completely objective discipline. But it's actually the least objective discipline, like in medical science, and that's a thing I really struggle with.

Not to get too on my high horse or anything, but sometimes I feel like I have more insight into the philosophy of science kind of things than the doctors who treat me. Because I'm aware of how science works as a process.

There are some psychiatrists I've had who have been very much, “Well, we'll try you on this med and that might not work but we don't really know.” But then I've had doctors who've acted like their word was complete gospel and not to be challenged, and definitely not by likes of me.

I'm aware of how medical research works, aware of all the problems with it. So to then be prescribed something and them be like, “If this doesn't work

for you, there's something wrong with you”, I’m like well, medicines are trialled in a very ineffective way [laughs]. I do need to just zip it now!

**Shan**

No no, don't worry, don't feel like you have to do that on our account at all. Eve did you have any final questions or should we end it on that note of psychiatry is a nebulous medical discipline [laughs] that doesn't have a concrete, yeah...

**Eve**

Yeah you know what, I do have some questions in my mind. There's so many things I want to ask, but I also want to be really mindful of energy levels, the fact that we've been sat here for a bit of time now, and also the fact that it is challenging to talk about some of this stuff and it is a bit of a wormhole. I'm mindful that there's certain things that I wanted to ask you both about the emotional impact of some of these conversations and the decision making around insight.

I guess Shan, I don't want to lose sight of you telling us you're having a crisis and you're actually really struggling right now. And I don't want that to get lost because of the way that you speak about your experiences. And that's my fear, well one of my many fears, is that when people are considered to have insight they are interpreted as not being in distress, or not being in acute distress. And that really concerns me.

The fact that you talked about being considered, quote unquote, low priority on a list. Because you speak clearly, you know, you describe things in such vivid detail about your experiences of multiplicity and plurality, and you talk about your voices so openly, so honestly, that maybe that gets lost. And for some reason people hear you, but don't hear you. That they don't acknowledge your pain and your distress. And I don't want to recreate that process by talking on an intellectual level.

**Shan**

Oh, no no, you're totally not at all. You're totally not at all. And I should say I did have one very good psychologist who really did try to meet me where I was with my distress. But then, because that was such an unfamiliar clinical experience I just lashed out at her completely and I was like, “I've no idea what's going on, you're trying to groom me, because I don't know what's going on here and you're being so different to all the other clinicians.” But no, I don't feel you're replicating that at all. So don't worry, I'm fine to answer any other questions or talk about anything more or listen to Alex talk.

**Eve**

If that's okay, how does it feel to then be on the receiving end of people downgrading you on a priority list when you are really in distress? And like you've described sometimes feeling suicidal and feeling very very in that pain?

**Shan**

It's really hard. And I think it goes back to what Alex was saying about being aware of austerity and cuts and pressures on the NHS. So for me, in the grand scheme of the NHS, and the levels of pressure, and especially having a sister who works in the NHS albeit not in psychiatry, you know I'm very acutely aware of why I am low priority, how that's happened. It's a systemic thing but it's not necessarily a personal slight on me, or people not caring. But at the same, again going back to that knowing and believing thing. So I can know that it's not a personal attack on me, or that it's a personal gripe with me, or that people are being negligent, but it does hurt to not be heard.

**Alex**

I know that's a question to Shan but I have real real struggle knowing that I am low priority. And there's a good reason for why I'm usually low priority in services. Or at least I have been for the last couple years, when I've had them. But knowing that, and being confronted with that, are two different things for one thing. And it's incredibly, I find it incredibly distressing. And I find it distressing on a day-to-day basis when I am in services, accessing services knowing that. It affects me accessing them in the first place, quite frequently.

I've had to be told to ring the doctor by family members, because when I've been in suicidal crises I have so little, obviously it's a big part of suicidality isn't it, like I have no self-worth. So to then know, and to have been told, that I'm relatively good, I'm relatively well considering. Knowing that I'm probably not going to get seen very quickly really fucks with me in those situations. It really really makes situations so much worse. Knowing all of this and having it in mind constantly. It has really significant ramifications for how I even experience crisis itself.

I really worry about what happens if I need to go back. I really worry about, if I become aware that I need to go back what I'll actually do with that awareness now.

**Shan**

I just wanted to chip in because I suddenly remembered something when you were talking about how demeaning it is Alex. And I just wanted to say some, not clinicians who have been directly overseeing me, but sometimes, it's not even the crisis team but just other people in the hospital. They kind of make

jokes. I don't think they mean to make jokes but it does come across as making a joke about my situation when I'm in a crisis.

I don't want to go into any triggering details but we were talking about plastic bags, for example, and then they were like, "Oh can you remove the plastic bags" And I was like, "Well no, no really." And then they were like "Oh, yeah, because now plastic bags are really expensive so your mum will get cross, haha." And I was like, "Well yes, that's what I'm thinking, but it's not funny and the way you said it was very flippant."

And it's really disempowering. In those situations I'm very good at making complaints for big things, but when it's those kind of micro aggressions I find it really hard to stand up for myself and be assertive. Because I feel so disenfranchised.

**Alex**

I've had inappropriate comments made directly to me by members of the crisis team and I've not said anything. It's hard to know what to say.

And I'm so conscious of coming across as angry now. Especially with the SIM [Serenity Integrated Mentoring] stuff. I'm really scared of that. But I mean, it's not something that will affect me probably, but that's obviously like part of having insight for me is about knowing what's going on in general. Obviously I'm aware of that. I have insight into the situation of policing in mental healthcare.

Actually I'm gonna wrap that up there cos I'm exhausted. I'm very tired and we're running out of time in this meeting. And also Shan's in a crisis.

**Shan**

Yeah I think I will have to end it on that note if that's alright Eve?

**Eve**

Absolutely. I just wanted to ask you Shan, do you want to have a chat afterwards? Just to talk about...

**Shan**

Would that be okay?

**Eve**

Absolutely!

**Shan**

Just a five, ten minute chat that would be really helpful.



**Eve**

Yeah absolutely. And likewise Alex if you wanna chat at some point we can have a solo chat. Let's keep in touch by email and I will send you the transcripts of the session, so if there's anything you want edited out I can do so. This is a living, breathing thing.

