Chapter 11: Knowing Too Much

Alex

Basically, what I wanted to say was I think obviously insight and autonomy are very kind of linked. To be classed as lacking insight is used as a rationale for stripping you of your autonomy as a patient. And your autonomous decisions are called into question when you are deemed to lack insight. [sighs]

I definitely understand why this happens. Like, I know I said safety measures are kind of, such as record keeping, end up too much being about legal culpability. But some people do end up potentially causing a lot of danger to themselves and other people, but mainly themselves.

I was definitely in a position where I was liable to get into some serious trouble and harm if I'd been allowed to just leave whenever. The thing is right, so when I lacked insight in hospital, when I genuinely genuinely would have, like in hindsight, if you'd asked me even two months later, “Do you have insight?” I’d be like, “Well, obviously not”. “Did you have insight then?” “No, definitely not”. I'm glad I was in a safe place. And I hated hospital, so like, for me to even say anything remotely like, “Yeah, to be fair, it was the only place I really could have been at that time.”

But the thing is, I went by a nickname for years. And it wasn't like an inappropriate name to be using. It wasn't like I walked in and insisted on everyone calling me “Shitballs” or something really crass or inappropriate. It's a fine name to use, it just wasn't the name I had on my records.

And I think after the first few days in hospital, after I'd been put on medication and I’d calmed down and stuff, it was the only thing that I would consistently recognise about myself was this name that wasn't [sighs] the name on the birth certificate and stuff. And whenever people would come in and visit me they'd be like, “I think you should probably call Alex by the name Alex wants to be called by”. And they never did.

And they'd see how distressed I was when they said it, and I'd be like, “That's not my name.” Or I wouldn't even respond sometimes. And at some points I would get very, very upset by it, because it was disorienting to me. Like no one had called me that name for a very, very long time. Not even my parents called me by that name.

They would not allow me that even. And it was so undignified and it was so upsetting. And it felt insulting. And it wouldn't have been that hard. The nurses were actually quite regular and they were quite consistent. And you know it's not hard to basically write, because they wrote all our names on a

whiteboard. They could easily have gone, “So and so prefers to be called so and so”, basically. It wouldn't have been hard. And it would have made such a difference to my stay in hospital. Like, it is a small thing. It’s not unreasonable, I don't think.

Shan
No, totally.

Alex
I think it was quite clinically significant that this was only thing I had any like, actually this was the one thing I did have insight for. It's the first thing I've got insight over. And they wouldn't even really accept that.

Shan
Did they accuse you of being delusional and thinking you were someone else or something?

Alex
I don't think they did. I think it was literally just like, does not compute. That's not the name that’s on the system. But people change names all the time for various reasons. And also it’s a very stable identity. Like I said, people had been calling me it for 10 years. Like it wasn't a whim. That was what everyone called me. Sometimes I think doctors, nurses and stuff would be confused when my parents said, “Oh, how’s Alex doing?” But they'd be like, “We don't have anyone called that here”.

I know that nurses are under a lot of pressure. I know clinicians are under a lot of pressure. I know mental health services have always been like this but I think austerity and the stress that the NHS is under it’s had this side effect of a lot of patients and service users etc. not really being seen as human. And that's OK because doctors are under so much stress or whatever that you can't even bring yourself around to respecting patients’ wishes in a very mundane way.

Shan
Yeah and it’s just really galling isn’t it? I mean, like you say, it wouldn’t have been a huge effort. You know, whatever strain they’re under it wouldn’t have been a big effort to make that small adjustment. And like you say they could have just put in brackets on the whiteboard or…

Alex
But I think it's telling to me how this adherence to insight, or how this obsession with always having to know best, or there's always, like, *processes.*

Some of those processes don't exist for very good reasons. Like you can understand what they're trying to do with them, but it’s rarely the actual practice. Like, it's where it rarely really comes through.

And I think a lot of that has to do with how little service users are actually consulted on stuff. Especially service users of institutions, or like inpatient facilities, I’m never sure of the right words anymore.

Shan
Yeah I think there is something to be said for just not making small adjustments, and small adjustments that would be really important.

You know, so I have this diagnosis of schizoaffective disorder, but I personally identify as multiple. But if I try to talk about multiplicity or plurality or dissociation in that type of sense to clinicians, they just really don't get it. So I have to end up labelling and being like, “Oh well, it’s this voice.” And then they’re like, “Oh the voices, the voices, yeah, yeah, yeah.”

And I’m like, “Well it’s not actually a voice, but you’re just not actually listening to what I'm trying to say. And you're not kind of meeting me on my own, you know, not that I’m saying they have to believe me, or that they even have to diagnose me, but just to pay that courtesy of being like, trying to meet me where I am.

Alex
I think good faith is really important. And I think a lot of the time it’s really lacking. Like everything you do has to be some kind of delusion if you have these sets of symptoms.

And sometimes it's not as exciting as that. Sometimes it can be a way you’ve made sense of the world that works for you and that is soothing for you. Or it could be something more significant. It could be a sense of culture around it.

I do genuinely think so many things within psychiatry and within mental health clinical practice can just be resolved by just assuming a patient is not trying to trick you. If someone says something that you don't know about, or like you're not really familiar with, or has a way of talking about themselves or said something to you, just maybe don't assume it's innately to do with a pathology. Or, just ask for information. If someone says something you don't necessarily recognise or like…

Shan
Or just even signposting to other people.

So I remember when, with my first psychiatrist, I was experiencing a lot of religious voices at that time, both positive and negative. And so I'd just kind of come in and be like, "Oh, God said this, and then there was this Jesus guy, but I don't think it was Jesus". And they're like, "Well, why do you think God is God, but Jesus is not Jesus". And I'm like, "Well Jesus didn't sound like Jesus". They're just like, "OK, what is going on?"

But that psychiatrist he said to me, "I don't believe in God, but I have seen patients who have, you know, something has happened in their spiritual life. And then suddenly this psychosis that I've been saying they've had has gone". So he was like, "I don't understand your frame of reference and I don't believe in it, but I'm going to send you to someone who does". So he put me in touch with one of the hospital chaplains for my area of London.

And not to say that the hospital chaplain believed me either, or necessarily thought I was hearing from God, but at least that psychiatrist was willing to be like, "This is something that I don't quite have a grasp on and I don't quite understand, but it's important to my patient, service user, whatever".

So I just kind of wish that all psychiatrists would, kind of like what you were just saying, you know there doesn't have to be this "I am all knowing psychiatrist". Just being like, "OK, this is a very tricky field of research and medical practice. And, you know, we don't have to have all the answers and we can admit that we don't know things."

Alex
I've had a similar issue in the past where I've always been quite politically engaged. And a lot of my mental illnesses, like experience of mental health and related symptoms, can be quite tethered to me reading the news too much, or me knowing quite a lot about current affairs or whatever, and being really worried about them.

And once I had a, this is on like, on just a primary care level, but I was really upset about something in the news. And they said, "Well, this person is not that bad are they?" And I was like, they were doing something that really was, it made sense that it would be specifically upsetting to me. I can't remember what it would have been about, but it feels very hard going into somewhere and being like, "These are my problems, this is what I'm struggling with". And them being like, "Well it's not that bad and you're just mentally ill." Like mental illness can often be very reactive, and can often be triggered by stuff around you.

One issue I had when I was in hospital I'd have like, not compulsions or obsessions, but all these mental flashpoints. And I'd talked to people who knew me at the time and they'd be like, "Well, you're really, really obsessed

with this happening”. And it's obviously my brain just processing what I'd seen in particular ways and making weird connections. I think my experience of psychosis has been, I would say, my brain just makes weird connections, really weird connections. And my brain always makes connections in an unusual unorthodox manner. But that’s autism. But my brain when I was psychotic did it to an actively distressing degree. And it did it to an unhelpful degree. And to a degree with where it stopped having real basis in the world around me.

But like, basically what I’m saying is I don’t like going into somewhere and being told that I'm just unwell. When the world is a stressful place and there’s a lot of unsettling, unhelpful things going on in it. If you’re already prone to anxiety, already prone to catastrophisation, if you’re already prone to some very distressing thought processes, to be constantly bombarded with information that's upsetting isn't going to help that.

And I don't think a GP going, “Actually, the climate isn't burning, the earth isn't burning, everything is fine, it’s you who’s the problem and it’s your way of processing that’s the problem.” Especially if you’re disabled or like a lot of my friends who have experiences of marginalisation do have legitimately big things to worry about in the world.

And I think like, obviously, I think it makes sense because clinicians have to be impartial and objective or they have to not bring too much of themselves into practice. But to act like mental health environments are just completely neutral, or like mental health happens in some kind of weird like…

Shan
Bubble.

Alex
Yeah like society’s completely neutral and nothing that happens in the world is a threat. And your brain isn't responding to a normal threat just in an unhelpful way. To pretend that is, like, I don't want to use word gaslighting. But it feels like…

Shan
Well no, I mean, it effectively is, isn’t it?

Alex
I mean, it effectively is. I just don’t want to minimise the experiences of people who’ve actually gone through that kind of relationship abuse. But it feels so disorienting. And I’m already disoriented if I’m going into a doctor being like, “I’m anxious. I’m already not sleeping.” And then to have someone come at me and be like, “Have you considered this isn’t a problem? [laughs] is even more so.

Shan
Yeah I definitely feel you on that one. So tricky to navigate all these things, isn't it? And especially when, because I think you mentioned earlier Alex that you're, you didn't use the word people pleaser but you talked about praise…

Alex
Yeah I really respond to praise. I have a heavy fawn response as a trauma mechanism.

Shan
I definitely feel like I'm a people pleaser. And I like to appease people. So if I feel like I'm saying something a bit too controversial, or if I'm showing, you know, not that they've ever told me I have too much insight, I think that would be a bit weird for a psychiatrist to say that.

Alex
I have been told that.

Shan
Oh have you?

Alex
No, I haven't been told I have too much insight, I have been told that I'm thinking too much about something or that I know too much about something. I literally did get told I was difficult because I knew too much!

Part of the reason I read so much is to make things easier for, I thought it was making things easier, I really wanted to be just fine to work with. I wanted them to think, "Oh yeah, I had this patient who's really cool!" [laughs] Not like really cool but like…

Shan
No I totally get what you're saying.

Alex
…a really bright young man! And sometimes I'd read my records and be like, "oh, cool, the doctor likes me! [laughs] That's nice, I like that." But obviously I shouldn't…

Shan
Yeah I know what you mean, I'm like that too!

Alex
But it is, yeah, sorry, I just, what were you about to say about people pleasing?

Shan
Oh, well, I can't remember actually, but I want to sidetrack off whatever I was gonna say anyway because I think there's an interesting thing that you've raised Alex a few times when you've been talking. And it's about this kind of knowing, like, knowing too much kind of thing, or like being able to use the kind of clinical terminology or the NICE guidelines or whatever.

And I do feel sometimes that gets me, not into trouble, per se, but I think I do have a reputation in my hospital as a bit of a shit stirrer. Because I did a big complaint, which got escalated to the chief executive of my hospital Trust. I think that's just how they do the complaints anyway. And then I think they kind of revised a service based on my case, even though they wouldn't admit it.

Basically in my particular borough there are two hospitals. And depending on the postcode of your GP, you either go to one or the other. So about five years ago, they decided to rearrange the way the hospitals worked. So there was going to be one hospital which was called MAP for Mood, Anxiety and Personality Disorders. And that would be in one hospital. And then there was going to be the TRIP team, which was Treatment and Recovery in Psychosis. And then they shuffled people about, splitting them from their psychiatrists and their nurses and social workers, whoever, according to what their diagnosis was.

So I ended up in the TRIP team, but my psychiatrist ended up in the MAP team. And so I was told that I couldn't see her anymore. And I was like, "Well, why?" And they were like, "Oh well, she's in this team, and you're in this team". And I was like, "But I have schizoaffective disorder, so I have a mood disorder and psychosis, so I should be in both teams. And actually my depression is more problematic than my voices, and if you'd actually bothered to ask my psychiatrist that she would have told you that too". And she's the only female psychiatrist in either of those two hospitals at all. So I had to do this big complaint to get her back.

And then about six to eight months later the hospitals went mysteriously back to the geographical location of your GP again. And when my psychiatrist, so when I got her back, she was like, "Oh, they showed me the letter you wrote and you were really angry. It was a really angry letter." And I was like, "Well yeah because I was really angry!" I was like, "What do you expect?" [laughs] She was saying I was really angry as if that was some kind of outrageous response. And I was like, "Well, you treat me like shit. I'm gonna fight back."

Alex

I haven't been pathologized, like discriminated against, for being angry. I actually, I've had many reasons to complain. Really, many reasons.

I mean I would have classed me saying I didn't want to be on medication as withdrawing consent. So I've withdrawn consent or made it clear I don't want to be on medication and it's continued.

The main psychiatrist I've had experience with didn't really understand, didn't ever give me advice on how to titrate or how to come off medication safely. He would just be like, "OK cool come off them, stop taking them". Like even with stuff like diazepam, benzodiazepines, he'd just be like "Cool come off them". I had to ring around pharmacists to get advice properly, because I knew that's not what you're supposed to do. And so I had a lot of reasons to raise issues. And I never did.

But in a Trust I was under they wouldn't let you change psychiatrists without at least giving a written explanation as to why. They wouldn't just take your word for it that it wasn't working. And at the time, like I've said before, my medication impacted my energy and my ability to finish a task basically, concentration and ability to assert myself and stuff. So I put it off. Like I kept just cancelling my appointment. I had to be readmitted for a different reason to what I was under. And I still got put on the psychosis team, even though my psychosis was one off.

And I felt like I was going to be labelled as such forever. Like I was really worried about it. But basically, the bureaucracy [sighs] is difficult. It wasn't even that I cared about being difficult at that point in time. It was that, I wanted my life back at that point. I was so worn out by being in services. I was so worn out by everything. I hated, at that point, I'm really tired of being just mentally ill. I mean obviously it isn't a walk in the park but I just felt so defined by it.

When I was on antipsychotics I didn't feel suicidal very often, because I didn't feel anything. But one of the things that became a really big trigger for me was feeling so alienated from my fundamental humanity, from anything that interested me. I didn't want to be in that role for the rest of my life. So I basically just, I didn't complain.

The only time I ever wrote was because I desperately needed help. I kept cancelling his appointment and I needed a different psychiatrist. Every time I thought about going to see him I had panic attacks. So I had to write this really long letter. And they just did it in the end. But there are good reasons that aren't necessarily negligence reasons.

I'm pretty sure it's very well established in the literature that a clinical relationship in terms of mental health, in terms of psychiatry, in terms of

psychology, really relies on trust and rapport between the patient and the clinician, between the service user and clinician. And to have a situation where that relationship isn't working is going to deeply impact treatment, is going to deeply impact recovery.

And to not have a system where you can say, "Look, this isn't working with this person, can I see someone else please?" is inherently not going to work, is inherently messing patients up. It's inherently really screwing people over.

I understand why it's difficult. The lack of consultants. The lack of whatever. But it is so fundamental to me for patients to actually be able to have that say and not have to jump through unnecessary hoops. Like, paperwork is hard for a lot of people in services. Advocacy is increasingly difficult to access. In my area it's really hard to get advocacy. I don't encounter a need for it as much as a lot of other people, but still there have been times, even with my ability to express myself, I could have done with it. Complaining's hard.

Shan
No it really is!

Alex
The fact that people, you hear a lot about how people in mental health services are too ready to complain, and that's why they have to make the process so difficult. But it's like, have you considered there's just a lot to complain about?