

Chapter 10: If You Eat Your Broccoli

Alex

My name's Alex. I am autistic. I've had contact with mental health services since I think I was 16 or so. Mostly that's been due to, like, suicidality, but I had to stay in an inpatient psychiatric ward for a while because I had a psychotic breakdown. Basically because I'd just exhausted myself, I think.

That was a good few years ago now and I kind of consider myself mostly recovered. I still have some mental health problems, but they're nowhere near as bad as they used to be. And yeah, that's broadly me I think.

Shan

Cool, thanks Alex for that introduction. So I'm Shan. I'm in my 30s. I'm a uni student in London. I've been hearing voices since I was five, so for over 25 years now. And I received a diagnosis of schizoaffective disorder mixed type when I was about 22. So I've been in the NHS outpatient system for 11 years. Yeah, because it took me a while to get a diagnosis. So I've been in the system for 11 years.

And yeah, I'm from London. So I'm perhaps in some ways on the more fortunate side of the postcode lottery, which is a huge gripe of mine, you know, that there's a postcode lottery in the first place. But if I start on that I'll rant forever! [laughs] So, I think, yeah, that's a bit about me.

Alex

So we're on roughly the same kind of decade plus sort of level. And I've had care in a few different localities. And like a lot of the time it is substantially different between places, which is incredibly bad.

So I suppose something I've found difficult is never having had a proper diagnosis. I've gone through a bunch and none of them have really settled, which is difficult because I can't use standard SSRIs. Which has very much complicated the care I've received.

Have you, cos you mentioned you're a student, have you experienced a difference in the way you've been treated when you've been a student and when you haven't been a student?

Shan

I think the fact that I'm a student completely confuses every psychiatrist I've ever met to be honest. They can't seem to get their head around the fact that someone with my diagnosis and someone who's been hearing voices for this long, and in sometimes to quite extreme levels, can study concurrently in the midst of that. So it confuses my unis, but it definitely confuses psychiatrists.

And actually, the first psychiatrist I ever had, he, so my parents were kind of, I live with my parents and they were kind of pushing me into doing an MA degree immediately after my undergraduate. So for context my psychosis, if we want to call it that, started when I was in my third year of my undergraduate. So when I left that uni, I was in quite a state of distress. But I was pushed into doing an MA course and my psychiatrist was actually like, "Oh yeah, that's definitely a good idea". Because he was like, "Oh, it gives her something to do so that she's not just listening to voices all day". Which I kind of get, but it's also quite stressful.

Alex

I have a similar kind of experience. A lot of my context is I've had difficulty with being in work. I have a lot of internalised issues around this. I have had very supportive line managers sometimes, but they've had to calm me down because I've just started crying about something that isn't to do with work. And I find work and my mental health don't necessarily get on very well, basically.

And I was out of work for a while, and my mental health team became very interested in the idea of me going back to work. Because they thought it would be the final piece of the puzzle to actually get my mental health back on track. And I was so scared of being in a work environment again. I was so scared about working formal hours. I was so scared about, like last time, even within this period of time, the last time I had my most significant dissociative episode since the psychosis in work.

So what you're saying about how into the idea of occupying yourself productively that mental health professionals can often be, even, and I think this goes into what we're supposed to be talking about today, which is insight, they have certain ideas about what recovery looks like.

And in order for you to be recovered in their eyes, you have to meet very, very normative criteria of what you do with your time. And that doesn't work, especially for neurodivergent people, that doesn't work. Often that's such a risk factor in and of itself. Like the work has to be something you're actually engaged with. And I think a lot of the time employability services, sort of within mental health services, really ignore that element of your wellbeing, if that makes sense?

Shan

Total sense Alex, because I think there's a kind of drive to just get you doing something and it doesn't really necessarily matter to them how good or bad a fit it is.

So I remember my hospital, so when I moved from the Early Intervention Service to the Community Mental Health team, I was talking to a duty nurse and I was really distressed and she was like, "You need a job!" And I was like, "I don't think this is a really appropriate suggestion when I'm in crisis". But she was adamant that she had to put me in touch with this work programme that is within the hospital. It's with a charity for people with mental health struggles to get back into work. And I was like, "Well, OK if you really insist that I do this whatever".

But yeah, it was a bit challenging for me. Because the mentor I was assigned, she's a really lovely lady, and I think she has a diagnosis of bipolar. So she kind of got what it's like to have mental health difficulties. But at the same time she was like, "Oh, you're doing a music degree so let's get you doing something to do with music".

And I was like, "Well actually, you know, yes I'm doing a music degree, but I've stopped playing my instruments completely". That was the first thing to go when my voices changed from just, you know, voices, into kind of more command voices, and more what would traditionally be called psychotic voices. So I was like, "Well actually I get what you're saying, and I get you think it's nice, but it doesn't necessarily fit with where I'm at at the moment."

Alex

I struggle with engaging in the kind of activities that I feel like make me a person when I'm having particular difficulties. And actually one of the things I found really difficult was after the breakdown, I was on very heavy duty medication for, I think it ended up being three years. Against my wishes, after a while of that, it was against my wishes. I was coming into my check-ins and being like, "OK cool, can I come off the medication now?" And they'd be like, "No, no, absolutely not, you're probably gonna be on it for the rest of your life". Looked up the clinical guidelines and then they told me I could come off it, basically because I hadn't had a relapse. But that only happened once I'd actually checked the guidelines.

And the thing is about medication, it stopped me doing anything creative for years. And also, the amount of time it took me in terms of like creative energy and even like interests, and just even passive things like TV or whatever. It also, like long term, even after coming off medication, it completely stole a lot of self-esteem away from me and the feeling that I could do anything like that.

But like I said earlier I kept getting sort of, "You know what will fix you? Work." I'm like, "Well, what will actually fix me is feeling I can engage in my hobbies again". I felt like they never really understood my interests. Maybe partly because my interests aren't stereotypically autistic, I think you said

something like a lot of how they perceive you actually mismatches fundamentally with, yeah, or maybe I said something, I don't know.

Shan

I think we both would have said something along those lines actually.

Alex

Because insight as a judgement is all about perception. It's about a clinical perception of you. So obviously if there's a fundamental mismatch between how they see you, and what's actually going on with you, then their assessment of your insight is fundamentally flawed. Like it's not a valid, like I know you use the word valid in like an academic sense, it's not, like a scientific sense...

Shan

Yeah a scientific sense...

Alex

...of the term, like, it's not useful information actually. Because it's inherently wrong.

Shan

Insight I find really kind of tricky as a thing to navigate. Because at first I was like, "Oh yay I have insight!" I'm a good patient. So, you know, I have insight therefore I am, like, special. I get a gold star or something!

Alex

Yeah! I really struggle because of how I respond to praise and validation. But in my experience that can so easily kind of like twist. Because you're like, "Oh, I'm a good patient". I think what a good patient does is read a lot about their mental illness, or about mental illness in general. And then suddenly, all of a sudden you've read too much and therefore you have compromised yourself as a patient. And suddenly how you get treated is very different. There's middle ground that clinicians are comfortable with...

Shan

And then there's a tipping point.

Alex

Yeah, so basically the longer you're in systems, like the more you are likely to start learning about them on your own time. For me it's a sense of, "I need to escape from this." That's how I cope, is by trying to figure out what's going on.

But you can easily push yourself out of the patient comfort zone. And then suddenly clinicians get a bit weird with you. I remember asking a question about like, I'd read my records. Like it's complicated reading your records, I find.

Shan

I've never done that, but yeah it would be quite interesting.

Alex

Actually to be honest I've tried to ask for records from the hospital and they've gone missing, apparently. Which is just like, bizarre. And frustrating. Because I have no memory of what happened.

They said on my record that my educational functioning was lower than my work functioning. And that messed with my brain a lot, because I didn't view myself as capable of being in employment at the time. At that moment in my recovery, I was still struggling to motivate myself to look after myself. But also it just felt like a blow to my self-esteem and my ego a bit. I've always been high achieving academically.

And then I asked, "What does this mean, and why is one lower than the other?" And I don't think I really got a sufficient answer. And there's only so much Googling you can do in those senses.

Shan

No because that kind of phrasing is very nebulous, isn't it? Be like, "Oh, this is lower than that". Where it's going back to what you were saying about how these aren't scientific quantitative things you can measure, you know? It's just all very nebulous and up to the whim of the psychiatrist and how they're feeling on the day. How they view you. What insight they think you have or don't have.

Alex

I sometimes wish psychiatrists would be more upfront about how subjective psychiatry is as a practice. I find it quite frustrating and quite difficult that they aren't, because it affects my trust sometimes. Like being presented with, "This is fact", and then you think, or you read, and it's not always clear-cut. But in order for that particular doctor patient relationship to work, there has to be that pretense.

I do worry about how much people end up like limited, how much patients and other people who have mental health problems get limited by that power imbalance, and that perception of the doctor as kind of all knowing and all correct.

I've had so many different diagnoses at this point, no one can figure out what's wrong with me really definitively. Who knows if anything is actually like, if I have a traditional mental illness. But it's also just, it's very hard. I find it very hard.

Shan

It definitely is very hard. I actually had to practically beat a diagnosis out of my psychiatrist. And I know some people really don't like diagnostic labels, but the reason I was so keen to have a diagnosis is because I just wanted, like, you know, everyone was talking as if it were just in my head, as if I was imagining things or acting out or things. And I just wanted there to be like, even if it wasn't a kind of brain chemistry rooted mental illness or whatever. I just wanted someone to, you know, have a framework of understanding. And I think for me having a diagnosis was part of that, but it just took so long.

And because no one really believed my version of what had happened to me at my undergrad uni, because they hadn't seen it. And then they were like, "Oh, well, she can come here well dressed, and she can come here by herself and without her parents sitting in, and she can talk eloquently, and she went to Oxford so she must be quite intelligent".

And they make all these kind of assumptions and then draw this picture of you. And then they're like, "Oh, well psychosis is like this, but she is like that, so therefore there can't be any kind of connection between these two things". And again, it's just so very nebulous, what does psychosis even mean?

Alex

Absolutely. I'm quite an atypical psychosis patient, because I have only had one episode, I am white, I don't have a significant history of substance misuse. Like, I feel like I don't exist most of the time in that sense. Because it's like, I think I'm at the point of having recovered now where it almost feels like it didn't happen. Sometimes I have to remind myself not to overdo things, because I'm actually at a higher risk as a result of it happening again. Even though it's been such a long time, I have to still bear that in mind.

A sort of flipside of the insight issue is that insight, if someone is genuinely lacking insight, and is genuinely lacking awareness, as a matter of safety good record keeping is vital. I don't mean that in a kind of legal culpability sense. Sometimes I get the impression that organisations, and sort of Trusts within the NHS, that's why they think they keep records. Or that's the most important thing about record keeping to them.

But I've really struggled with the fact that there's no real clinical records from my admission. Because I have no understanding of what happened or what I did. If something serious happened in hospital, I would have no way of knowing. Because all I have to actually go on is what my family observed, like

my family have told me stories of times they visited. But that's like 10 hours of my waking day that's not accounted for.

I have a really vivid recollection of certain things. I was restrained quite a lot, which is a whole different thing. And I have a lot of traumatic issues around being restrained now. Like there's things that I have triggers for now, which I might not even be aware of the things that happened to me and the things that are traumatic. Like, I don't think I got triggered before hospital, in the same way.

Because of that lack of record keeping I can't account for things that happened when I really truly lacked insight. There were so many times when they were trying to sort of like say, "Alex doesn't have insight". Or like "Alex lacks a lot of insight into his condition."

Actually after the hospital when I did have insight I could at that time quite cogently explain what happened to me and what my symptoms were and how they were different from, I mean, even 10 years before I got hospitalised I was interested in surveillance. I'm interested in things like surveillance creep and human rights abuses and stuff like that.

But I've always been interested in that, even before, like when I was just attending services, because I was suicidal constantly they would ask me if I was paranoid. And I'd be like I don't, what counts as paranoia? Like, I'm conscious that there's a lot of security cameras, but we have the highest CCTV rate in Europe. And they were like, "Well, paranoia is kind of like this".

And then I started being actually genuinely paranoid. And now I do know the difference. And I think even at that time I would have been able to tell you, "There's a lot of horrible things in the world and I'm paranoid about data security and stuff, but there's legislation around that, it's an obviously OK thing to be paranoid."

I could quite coherently explain, but I was still, because I think this was around the time I started being like, "Is it really necessary for me to be on medication for the rest of my life?" It's like, basically, "Alex has started not wanting to be on medication. And Alex has started lacking insight into how long he's gonna be on medication for, i.e. his entire life". Have I even said that right?

Shan

I get what you mean, because I had a kind of similar thing. I got sent a psychiatrist appointment about maybe a year and a half, maybe two years ago. And it was with a psychiatrist I'd never seen before. And I was like, "Oh, I think this is a male psychiatrist". And I struggled with having males on my team. But I was like, "Oh it's a South Asian name, so maybe he'll understand

my family background”, which some people really can't grasp their heads around. Sorry I forgot to mention in my introduction that I'm South Asian.

Anyway, so I went to meet the psychiatrist, and thankfully there was a junior female psychiatrist there and the implication was that the female psychiatrist was going to do all the talking and the male psychiatrist was just listening in because he's a consultant. And I was like, “OK I'm cool with that. That's fine”.

And I always make notes for my appointment. So I took the notes in and I gave one to each of the psychiatrists. And the female psychiatrist is talking to me and asking me questions. And the male psychiatrist is reading the notes. And then he's suddenly to me, “You've written here that you were hypomanic, do you know what your diagnosis is?” And I was like, “Yeah, schizoaffective disorder”. And he was like, “And do you know what that means?” And I was like, “Yes, because I wasn't born yesterday and I go and read up on these things”.

He was so kind of like, not aggressive, but it kind of was a bit aggressive actually. And the way he was talking was very kind of physical, like he was leaning towards me. And I was like, OK this really isn't helping with my kind of like, issues about, you know, male psychiatrists or whatever.

And then he was like to me, “Oh, why are you on this medication that you're on?” And I said, “Well, that's what my previous consultant put me on”. And he was like, “That's totally wrong”. And I was like, “Well, you've just met me and she had me for like, nearly four years”. And so I was like, “OK”.

Whatever the medication he wanted to put me on was a medication that could make me infertile. And he was like, “Because you want to stick with these medications that you shouldn't be on in the first place and you want to not change your meds so therefore you lack insight, but you have enough insight to consent to being on a medication that could make you infertile later on. And you've got enough insight to sign this piece of paper and understand what it means”.

And luckily he didn't put the piece of paper right in front of me, because he was like, “Oh, you'll have to sign that later when we get round to changing your meds”. And I was like, I'm not signing this shitty piece of paper, you know, what do you think you're on about?

Luckily I never saw him again, and then I got moved to a different team. So it was fine. But yeah it was that whole kind of insight, like you have insight for this, but you don't have insight for that. And it's like, well, either I do have insight or I don't. It can't be insight for specific things.

Alex

They're one step away from saying, "As long as you eat your broccoli, you've got insight. If you don't eat your broccoli, no insight for you".

Shan

That's a really good analogy Alex!

Bethlem
Gallery

Maudsley
Charity

Backing
Better
Mental
Health.

NHS
South London
and Maudsley
NHS Foundation Trust

mbj
Mental Health
and Justice

w
wellcome

KING'S
College
LONDON