

## Chapter 19: What If I Go?

### Eve

I think there's something interesting around the sense that some of the conversations that happen around insight, that if somebody is deemed, from a clinical perspective, if somebody is deemed insightful, it means, or it's translated, somehow, into, well they can't be in that much distress then.

### Anon

Wellness. It's translated into wellness. And it's translated into a lack of symptoms, or an absence of symptoms, and an absence of, as you say, of distress. And I've got many examples from my professional life where that's happened. Where people have come to the ward or whichever, not just where I am now but throughout my career so far, and people have genuinely said, "I don't know why this person's here". Now that you can read two ways.

There's one situation that's happening for me at the moment where unanimously the team that I work with are saying, "This person does not need to be in hospital". That's a good thing. That's what happens in a good way. And we're in the process of going back to the people who referred them and saying, "We're not seeing what you think we should be seeing, this person is healthy and happy, has some challenges, but knows about them". Again, there's that pesky insight thing. "Gets where their struggles are, has a plan to manage them, then don't really need to be in hospital". That's when it happens in a good way.

But it also happens on the flip. Where somebody will come, and I have one very vivid memory from my previous working, of somebody who came to the ward that I was working on describing their symptoms, and they were psychotic symptoms, they were voice hearing, it was derogatory voice hearing, really distressing stuff, but there was an absence of distress. They weren't outwardly showing distress. They were very high functioning. Again, pesky clinical phrase "high functioning". They were able to do stuff, is what that means.

### Eve

You're using air quotes again.

### Anon

Yeah I do a lot of that, because that's what they mean, to me, those technical words are just quotations and don't really mean a lot. You know this was a person, a young person, who was able to do stuff, was able to function. And yet they were telling us they had these really distressing things. And the team that I worked with couldn't reconcile that. They couldn't see.

And again, this was mentioned, university student. How can a university student who's successful be struggling with their mental health? What is it with this presumption? That to have a mental health difficulty or to be in a mental health crisis you can't be able to achieve anything. The two can't run concurrently. It's bollocks, quite frankly.

And in answer to your question that's what we see, this idea that if you're not showing us your distress, then you can't be experiencing it. Distress is a really nuanced, again, really nuanced word. You can show distress in many different ways. You don't have to be bursting into tears every five minutes and screaming the place down. Distress can be much more subtle and much more insidious than that. But those are the ones that we miss.

**Eve**

Yeah I think that's a really powerful example.

**Anon**

You know, why are we looking for people to be in distress? Why do we think that if you have a, oh there's that classic thing of, you know, if you have a job or you've got an education or you're in school or in university or you got a job, you've got some friends, you might have a partner, you're successful, you know, ticking off life goals, right? "You've ticked off a lot of the key life goals that we're supposed to tick off and yet you're telling us that you're really really struggling? I don't see your struggle, because your life looks pretty good to me."

Again, that happens a lot. You know, why do people need to prove to us that they are distressed? Why do they need to prove to us that something is going "wrong"? And again, wrong is in inverted commas, because that's a bad word to use. But it's the only one that comes to mind.

**Eve**

How do you prove that you are distressed, and I'm tempted to say *worthy* of support? That's very loaded.

**Anon**

It takes you back to playing the game. And this is why there are so many instances where, and again my experience as a professional has been exclusively in hospitals so I can only speak from that as my environment, things get worse often in hospital because people have to prove.

So they might watch others, they might watch out for other people's behaviours, and go, ooh OK, where that person was telling the staff that they were experiencing that and that seemed to get them what they felt they needed, so maybe I should try that. And the majority of people for whom, and again, this is a technical word, air quoted, technical word, who have

“maladaptive coping strategies”, I can guarantee you they learned them in hospital. Guarantee you that's where they learned them, because the system made them learn.

They needed something they weren't getting, so they had to find a way of adapting to get what they feel they needed. That can't be good for people. For people to feel that they have to again, play this game. What do I need to say? What are the trigger words, trigger phrases, or behaviours that I need to exhibit to tell this team of people what I'm going through? Because I can't tell them in so many words, because I'm not capable of that, because it's too much. I can't use my words, I need to use my actions. So how can I prove. It's about proving, and this weird way of having to prove that one is in distress.

### **Eve**

Are psychiatric hospitals safe places to be distressed?

### **Anon**

No. Generally, generalising, no. Because distress equals symptom. Distress gets medicated, unless you're incredibly lucky and you have some talking therapy. *That* doesn't happen very often in wards. You might have a psychologist that pops up every now and again, but they're not there all the time. And that's not the primary line of defense, as it were. It's not the primary line of treatment. So no, they're not safe. They don't feel safe places to be in distress. But then in order to be in them, you have to prove that you're distressed.

So you're again, one is again in this catch 22 of having to prove they're distressed but not feeling safe to do that. And then you find subtler, potentially, riskier ways to prove you're in distress that aren't quite so out there, feel more contained, but are actually, are actually worse for the individual. They're worse coping mechanisms to develop. They're less help – again I don't know if that's the right word - they're less helpful, they're less, they're riskier.

But you get caught in doing that. Get caught in this cycle of having to prove your distress but not feeling safe, so finding other ways to show it. And then you're not always able to say what you really need to say or to show what you really need to show because you're finding new ways of doing it. Again, I don't know if that makes sense. I'm kind of rambling.

### **Eve**

No, it does. It does. And I'm almost now feeling like I want to come full circle and ask you again about the impact on you, someone going into these environments that don't feel necessarily helpful or safe. How you're doing that.

## **Anon**

I've started to think I can't do it anymore. [pause] Genuinely. I'm stuck between not liking so many things about the system but being confident in the fact that I don't conform to those things. So I'm hoping to make a better experience for people. If I leave, who else is going to do that?

And I'm not saying I'm the only one. I'm not putting myself on a pedestal, just to be really clear. There are 1000s of clinicians who feel the way that I feel. I'm sure there are. I know there are. Who are doing that, who are doing the good stuff, who are being nuanced, and who are being less prescriptive, and who are trying to read between the lines and meet people where they are and be open to changing their clinical mind.

But me, where I am, and again I'm not suggesting that I'm the only person in the team that I work in now, there are other people who are doing the same thing and who are trying to do the same thing. But if I leave, how much of an impact? It may not have, maybe I'm inflating my own importance, it might not have any impact at all. If I leave, it might turn out that I'm not making any difference.

But what if I am? What if my presence and my perspective is helping, in some small way, make a positive change? If I leave, can I sit with that? Can I sit with the fact that I know those things I don't like about the system are gonna keep being perpetuated? That's one side of my mind and my coin.

The other side is I know I can't change it while I'm in the system. There's very little I can do, to your point that you made earlier about what things can you do, you know, to be an outlier and to make those changes, very few when you're physically there, because your job is your job. And I have to remember that I'm paid to conform. To a certain degree, I'm paid to tow a particular line. And to come at things from a particular perspective on some grander stuff. Day to day I can say some stuff that maybe falls out of that line. But generally speaking, I have to follow suit, I have to follow a protocol.

So my other side is thinking, I don't know how many more weeks or years I can go into that environment, see the things I see, feel slightly powerless to change it, but know that I'm trying at least to change it. But then also know that I can't really change it unless I go big. Unless I go to the service development end. Come out of the service itself, stop being a clinician, a job I love, I mean I genuinely love what I get to do as me, but I know I can't make the changes that we need to make while I'm doing it. Because I'm tied by the system. I'm tied by the Trust values. I'm tied by all of that stuff that I'm told I have to abide by.

If I leave, maybe I've got a small chance of finding a team of people who feel like me, going into policy, which scares me, like, really scares me. But maybe that's the way to do it. Maybe I need to say 10 years of being in the environment's enough. Doesn't mean I'll never come back. But then where do I, how do I find that?

You know, I've been privileged enough in my most recent role and a role previously, actually two roles, to be part of some research. Some development stuff. Well, supposedly research and development. I've done the research bit. I've yet to see where that's developing. I've yet to see how service development is happening, because of the question that we've asked and the thing we've got published, which is a really important question. It's really important stuff that we've published and we've put out there and I'm hoping to get something else published, another question that I've tried to answer and suggestions I've tried to make. That's the research bit, great. But where's the development? I haven't seen that yet. We've just put it away.

And I've realised having put such an importance and placed such an importance on research, I've realised that actually people just do it to get their names on papers. They don't really, they care, but they don't, their priority isn't necessarily to actually implement change. It's just to put the question out there. And I don't see the point of putting a question out there unless I can actually work to answer it and make a difference.

That kind of is driving me towards the, the second part of my brain which is telling me to come out and find people who are doing that. Find people who are making an actual difference in terms of policy development. But then I get torn back! And I worry that policy doesn't really make a difference. Because I've seen it. I've seen how policies are written. And they don't help. They're just guidelines. They don't do anything.

A relative of mine works in scientific policy. And his whole job is to take research and turn it into usable policy. That's his whole job. It's what he's paid to do. Turn it into usable policy. He does that, but then those policies don't get distributed. They just sit. And they don't do anything. And I find myself kind of arguing with him going, I need you to show me the point of this research, because you've created this policy, but where is it? Why is it not being implemented? Oh because of the system. Why did you bother? So I'm stuck. I'm stuck. Not really feeling like I make [sighs], I don't know what difference I actually make to people. I don't know what difference, what change, I actually bring about for people.

You know, we pride ourselves in inpatient services in saying, particularly in jobs like mine in OT, we pride ourselves in saying we give people their skills back. Their skills for independent living, living in the community, whatever you want to call it. If I actually think about the number of patients that have

been able to do that after I've worked with them, it's very few. And that's because of the system that we work with.

And I am kind of tired. After 10 years, which is very relatively little, you know, I've got a lot more years left. This is a career I'm not going to retire from necessarily for a long, long time yet. But is this, am I doing enough? Is where I'm, yeah, where I am at the moment is like, whatever change I'm able to make now is that enough of a change? Or can I find somewhere else to make a bigger change? If the answer's no, then fine I'll keep doing what I'm doing. But do I not have a duty to try and find the place where I can make the biggest change? And make the biggest impact to the positive.

But also I've got to find people that agree with me. That's a struggle in itself. People are very quick to, when you're having a cup of coffee with your friends at lunchtime, with your colleagues, they're very quick to say they agree with you but actually do they agree enough to step out of what they're currently doing? Break out of that mould and challenge it? Knowing that they might not be allowed back in again.

That's kind of only just occurred to me [laughs] whilst I've been talking. That if I do go out, if I come out of the clinical world, clinical setting as an OT, and I find a group of people who are challenging the system, is the system going to let me back again? If I actually do I want to do, and again maybe I'm inflating my own importance and my own ego, but if I am actually able to make some changes are they gonna let me back in? Will I still belong to this group of people that I've worked for and with for the last 10 years? Will they not want me anymore? Will the people that I work for who are the most important people, the patients, will they actually want me back? And will my colleagues want me back? Will the people I work with, accept me back if I go off and do these things?

I'd love to think so, but actually it's just occurring to me that you read it all the time. You read about people who have whistle blown or who have, you know, despite the fact that we have these policies in place within the NHS, the whistleblowing policy, they don't work in practice. That does not work. People are punished, even though there is a policy that says they shouldn't be and they won't be. I've seen it happen. I've seen people bring things to light that are truly, I mean I'm not talking about anything necessarily inherently bad. I'm not talking about misuse of power or abuses. I'm just talking about a system that I don't think works very well. But I know of people who have seen genuine miscarriages of justice and misuse of power and abusive behaviours, who have used that safeguarded policy to speak out and they've never worked again. So how do you do it?

And it's funny how a conversation can make you suddenly realise that [laughs]. I hadn't thought about it like that.

**Eve**

When you're asking yourself, if I leave, and try and push for the changes I believe in, will they let me back in, how does that question make you feel?

**Anon**

Really, really anxious, because I'm one of those rare people, and I recognise I'm in a privileged position, I knew what I wanted to do when I was 12. I spoke to someone who was an OT, not in mental health, but in another setting, and I always knew I kind of, I thought about being a nurse at one point, but I kind of always knew the type of thing I wanted to do. And I heard this woman who was in her 50s, and she talked me through the kind of stuff she did. And I had a lightbulb moment. And I said that very day, "That's my job. That is what I want to do."

And it's the only thing I've ever considered doing. I did a degree that was specific in that job. It's lucky enough that that existed. I don't have a general degree, I have a very specific degree. I've worked incredibly hard to be the kind of OT that I am. You know, to get to the point that I've got to has been a challenge. And I've worked really hard at it. And I can't imagine not doing this job. So that's kind of scary.

Because what if, and again, inflating my own sense of importance here, but what if me going out and challenging things that I feel need to be challenged means I can't do that job anymore. Then what will I do? There's nothing else I've ever wanted to do. There's nothing else I've ever thought I *could* do.

So it's scary. It's very, very scary. But maybe that's a good thing. Maybe the best things, maybe the best changes and the best experiences come from being afraid. Maybe that should be my motivation. And I'll deal with whatever comes next.

I'm not even sure it's possible. I'm not sure it's possible to find a role that can implement that level of change, because I'm not sure the system welcomes it. I don't think it exists. I don't even know if it exists.

**Eve**

If you could give the mental health system a prescription for change, what would it be?

**Anon**

[sighs] Oh my goodness. That's a question [sighs]. I would, and I don't know if this isn't, I guess this isn't quite a prescription as such, but maybe it is, I don't know can I write this on a prescription? I would get rid of all wards. All inpatient units. Get rid of them. People are not designed to live in confined spaces, whatever they're going through. People are not designed to *exist* in

those environments. There may be a few people who need that level of containment. So they might still exist in the few, but it shouldn't be standard that people who are going through something get processed onto a ward. That just shouldn't be standard practice.

I would bring back day hospitals. And day units. And I would plough as much money as I could into community services. I've realised that's not quite a prescription, I don't know if I'd need to maybe rethink that one. What could I give as a prescription? [sighs] Everything I'm thinking of just sounds really obvious. You know, it's just about, so what would I give as a prescription to a particular person or to the service itself?

**Eve**

To the system itself.

**Anon**

To the *system* itself. [sighs] Think critically. Enquire. Think. Consider. Challenge. It would be a series of words, I guess. All the things I think we need to do. Look inwardly. Challenge what we do. Ask why. Be enquiring. Why is that the standard line of treatment? Does that necessarily need, ah! That's a really hard question. And it's a question I probably need to ponder and come back to having created a prescription. I don't know if you've asked other people that question and they've been able to do it right away. [laughs]

**Eve**

[laughs] It just occurred to me.

**Anon**

But that's a hard one. You know, would it be? Because a prescription is, you know, it's an exercise I've actually asked other people to do. If you could prescribe anything for yourself, what would it be? And it might be 10 minutes of sunshine. Or it might be a hug. Or, you know, what do you need today. There's an exercise we have where I am at the moment with my team. I've got like a chart full of little, they're like raffle tickets, and each raffle ticket has a different word on it. And the board says, take what you need. Take what you need today. And each raffle ticket will have something like respect, warmth, kindness, courage and you're taking what you need. I don't know what the system would be willing to take. And that's why I find it really hard to write a prescription.

Because again, like you were saying earlier, I've got feet in both camps, I've got an understanding of how the system works and a knowledge that it's really closed off from people recommending new things. So I don't really even know how to write the prescription because a prescription is only as good as the person who picks it up. And the person who cashes it.

So until I meet that, I don't, that's not helpful, is it? I don't know is the honest answer! I don't know what I would write as a prescription for the mental health services across the NHS for all the mental health sector. I don't know what I would write.

### **Eve**

Another question that's in my mind that I have asked some other people is what does justice look like to you?

### **Anon**

Justice like insight is a changeable thing, and a personal thing. And I can only really, I don't know. I think if you'd asked me 10 years ago, what does justice look like? Because I guess automatically what I go to is justice for my patients. But that's not the question. That's not what you asked. But that's where I go to. If you'd asked me 10 years ago, before I started this job, I'd have probably been able to tell you what it meant. But now I don't know, because it's muddied by so many other people's definitions. I don't think I have my own. Honestly. And that's my honest answer. I don't think I have my own definition of what it means to me. Because it's influenced by so many other experiences and so many other people's opinions. I can't eradicate those. They've informed so much of what I believe now that I don't think I could give you my honest, true answer of what justice means.

That may be a cop out answer. But it's the only one I've got right now. I mean, I could say it means getting what you want. That's a really simplistic way of looking at justice. Justice should be getting what's right. But what is right? And that's the bit for me that's got muddied and got lost. I used to have a really strong sense of what was right, in the field.

I guess it's hard, are you asking me, me? Just me? Forgetting the rest of this conversation? Or are you asking me in the context of what I do? Because if you're asking me in the context of what I do, I have no idea anymore. I don't know what that means anymore.

But if you're asking just me as an individual, justice depends on the person who's seeking it. There is no definition of justice. Justice to me is different. It's what's right. Justice is what's right and what's just. You know, the first part of that word is just. If something is just then it is right, it's appropriate, it's proportionate, it's the right thing. But who gets to decide what the right thing is? The person who's seeking it.

If someone is seeking justice, I don't have a right to tell him what that should look like. I can't actually explain. It's funny, I thought if I separated the two I really thought I'd be able to give you my personal definition. I thought my professional work related definition was going to be hard. But my personal

definition would be easy. But actually, it's not. It depends on what I'm seeking. What I'm seeking justice for.

It's the right thing. Whatever the right thing is, it's just the right thing. Which is a really unhelpful response, but can't really be quantified, but it is, I genuinely feel, again, me personally, putting the rest of this conversation aside, that one will know when one finds justice. One knows what, even if, like me, they can't explain it, they'll know it when they find it. And we can seek justice for so many different things. In our everyday life, you know, justice, people ask, you know, the question why, why does this happen?

Seeking an understanding is like seeking justice. You know, seeking, why why do these things happen on these grand scales? Why have we got a climate crisis? We need to find justice for that. But each person's individual thing? I don't believe there is a definition actually is what I'm coming to. It depends on what you're asking for. If you give me a scenario and you say, what does justice look like? If you're in this situation, I'll be able to tell you, but I think it's changeable. I think you just know. You know when you've found it. You know when you've supported someone else to find it. But I don't think you can quantify it or put it into words. It's a feeling. Justice is a feeling, rather than a thing you can vocalise.

