Chapter 17: The Odd Fish

Anon
We as human beings don't like to be confined. Whatever we're going through, we don't like to be confined. So if you do that to a person if they are struggling with something, they're likely to start to struggle more.

And then you're not getting a true representation of the person. You're getting an exaggerated version, which I think we see on wards all the time. We end up making their issues worse, so we can then treat them. That's how it feels anyway. I'm sure my colleagues would disagree, but that's how it feels.

Eve
Have you vocalised these kinds of concerns?

Anon
Yep.

Eve
What's been the response?

Anon
It's hospital policy. We can't change it. It's hospital policy. Actually, it's not hospital policy. It's the ward's policy. The ward gets to change the policy. But people don't want to, because in order to change a policy you have to think and you have to critically analyse, and you have to be critical of yourself as a team. And we don't like to do that. We don't like to think we're getting it wrong. And that's one of our biggest downfalls. That's one of the biggest issues in mental health services. We cannot admit when we're doing it wrong. And that's human nature, but on a systemic scale.

You know, we as individuals in our everyday lives don't really like to admit we've got stuff wrong, but put all of those individuals together in a system we don't want to admit the system is getting anything wrong, because if we admit it we have to change it. And nine times out of ten we don't know *how* to change it. We don't know what to change it *for*.

And again, that's kind of how I feel, I know when something feels wrong, doesn't necessarily mean I know the solution. Or I know what we should be doing. But I know what we're doing feels wrong. And we need to discuss that. And we need to be open to that.

Eve
Are you a bit of an outlier in your team?

Anon
Sometimes. I probably was more so before, earlier in my career, and I got bitten for it. And I suffered for it, professionally. And so that makes it even more difficult to be the outlier. To be the person who's challenging. To be the questioner. Because always in the back of my mind I have the memory of what happened before, and that makes me kind of cross because that shouldn't stop me. That shouldn't be a reason for me to sit back and to just accept, which is why I guess I do challenge but I try to challenge in softer ways than maybe I did before. Which is in itself a bit of an issue.

Eve
It feels like you're walking a very difficult path. A treacherous one.

Anon
That's why, looking at my notes and hearing the people's words, nothing surprised me. And I keep coming back to that. That's the thing that I keep coming back to. Why wasn't I surprised by any of that? Was I not surprised because I've become numb to it? It's been 10 years, 10 ish years, that I've worked in the same kind of services, in the same kind of environments. Does that mean that for those last 10 odd years I've seen this, and I've heard this, and so now it doesn't surprise me anymore?

And that can't be a good thing. And I keep coming back to that. That was the thing I was left with. Just this, yeah, that's really familiar, that's an everyday experience, you know, the things that people spoke about. Just, I see it every day and I have done for years. Which means we've not moved forward. We've not changed anything about what we do in those types of services. And if this is what people are struggling with, and these are the themes that people say are troubling to them, and have a negative impact on them, why are we still 10 odd, I mean it won't be 10 odd it's just the years I've been working in those environments, why are they still experiences people are having? Because those are negative experiences.

Eve
Can you answer your own question? Do you have an inkling as to why that is the case?

Anon
I think there are so [sighs] many incentives to keep things as they are. And again it comes down to admitting. To admit that we're getting things wrong, we have to be really brave. And this is a whole system. This isn't just one ward. These aren't people who are all from the same team. These are people who were supported by a huge breadth of professionals under different services with different aims and objectives. And *all* of the comments are the

same. So for us to, on an NHS scale, say this is a problem, we've got to dismantle the whole thing and start again. That really is the only way we can change.

And the fact that our Mental Health Act has just been reviewed for the first time in over 30 years, and nothing has been amended, they have made no changes to the key framework that supports these people, tells you an awful lot. We're not prepared, or our great leaders who lead our services and, you know, both directly and indirectly on a political level, but also on a clinical level. Clinicians had a hand in, you know, the government reviewing the Mental Health Act, clinicians were directly involved in the review process, and not one of them said, there's anything I would change. I look at that framework, and there's a lot I would change.

And I find it very difficult to believe that those clinicians genuinely don't see anything that needs to be changed or to be amended or to be questioned. My concern is that they identified some stuff that they may have written down, but thought, “There's no point me mentioning this, because it's not going to get changed. I'm going to be the odd fish, the one that challenges the system, and I don't want to be the one that challenges the system.” So we're going to carry on for the next 30 odd years with the same framework. How is that sensible? How is that right?

And it's interesting having this conversation now, after that review process has taken place. I was really hopeful when I heard that it was being reviewed, I thought, “Oh, this is the opportunity now to really think critically about what it's there for.” How is it best used? Because I agree these things need a framework. But we had such an opportunity to challenge it and to think about how we could better use it in the future. Because the world is a different place now, things have moved on. But why hasn't that moved on?

Take you back to medication. Why hasn't that moved on? We're still using the medication we used when the Mental Health Act was first created, when sectioning first became a thing. The atypical antipsychotics are still the ones we use. *That* can't be right. You think about all the other pharmacological treatments, all the other drugs that have been changed and developed in *every* single other clinical area, except this one.

And there’s something holding us back. There's something stopping us, as you say, your question is why are we not making these changes? There's got to be some bigger, some bigger picture here. I sound like a conspiracy theorist when I say that [laughs]. But there's got to be something else driving the fact that it’s not being changed. It's not being challenged.

Eve
What are the things that you really want to see changed?

Anon
The focus on, and again it takes me back to some of what was said in the other interviews, what do we as the care teams and as the healthcare professionals, what do we place the most importance on? Do we place the most importance on symptoms, or on wellbeing and on functioning, and people's ability to live the lives they want to live? At the moment all of the focus is on symptoms. And there's very little opportunity to say, “Could we maybe just support that person to live with those? Do we have to actually get rid of them?” Again, it's on an individual basis. I think that's the thing I would change the most. That was a long-winded way of saying it needs to be a more individualised and personalised process.

You can't just fit people into an ICD, into an international classification, and say this is the diagnosis that they have therefore this is the treatment they will receive, which is still what we do. It's a table. And when you look at that framework, you have your list of most typical diagnoses and there's recommended treatment, and unsuitable treatment or not recommended. And guidelines state, you have to follow what's recommended. And that's for every single person who has that primary diagnosis, no matter their background, their experience, their thoughts, their emotions, their goals, their objectives. That's what we do. That came through in the conversations.

You know, something that resonated with me, I guess because I'm an OT, someone spoke about interests. And it really struck me. They were talking about how lots of times there would be, you know, “Oh, you're interested in music?” “Well, no, that was a long time ago.” “Oh, you're interested in music. So we're going to refer you to a music group.” “Yeah I’m no longer interested in that. That's not where I need to be right now. I haven't played any music for a long, long time. So actually, that's not applicable.” And then as soon as they said that, they were considered to be non-engaging in something they were supposed to be interested in. And reading that really riled me up because I was just, again, it felt so familiar.

You know, the first thing I'm told about is somebody's history. As soon as I meet a new person in the place that I work, I'm told their history, I'm told their *past*. I'm not told their present. And I'm encouraged to use their past to help formulate the way I will support that person. That makes no sense to me. My past isn't where I am now. It may inform where I am now. But actually I'd much rather, if I were that person, if I were on the other end of the conversation, pick me up where you find me today. Help me move forward. And then establish that in order to help me move forward, you need to understand something about before, about the past.”

We keep people stuck in their past experiences. And again that came through, this idea that taking ownership, taking ownership of the things these

people have done, either to themselves or to others, the risky things that they have done in the past, the behaviours that they have engaged with in the past, they are stuck with those things. And we never let them forget it. We never let them forget what they did before. That time when things were so bad that they did something to harm themselves, or whatever it might be. Can we stop bringing that up? Because that was then, and it's not necessarily now. It might be, but it might not be. We kind of make this presumption that people's past needs to be brought into the present. And that's quite a hostile environment. It's quite a threat to a lot of people. And that came through.

And those are conversations I've had with my own patients and people I've worked with. You know, stop using my past as a weapon against me. I'm not that person anymore. I may still have some of the same struggles. But I'm not that person anymore. And you need to meet me where I am now. Stop dragging me back to what happened before and using that as a weapon. That came through, not in, I'm paraphrasing the words, but that's how it felt when I was reading a lot of the words from the conversations.

Becoming a people pleaser came through too. Having to tick a box. Feeling that you have to play a game. We shouldn't make people feel that they have to say certain things. And that works both ways. You know, people, were talking about feeling that they have to play the game in order to get what they need. But also there was this sense that they didn't really know what game they were playing at all. They didn't know the rules. A game had been set. And me as the badge wearer, I know the rules. But the person who is playing against me, I haven't told them the rules. I haven't told them what the aim of this game is, or how you win it. And that came through, this idea that we have to, or that people have found that they've had to either concur with their care team, their psychiatrist, whoever it might be. And if they challenged the game then they were told that they didn't understand and that they lacked insight, just because they disagreed. They had a different opinion.

What was really interesting was that somebody, and again it was this insight thing, there was one particular person who *totally* understood that there was a point at which they themselves felt they lacked insight. One particular person said this. That's quite rare, in my experience, to have somebody who can actually say, “Yeah, when those decisions were made on my behalf, they were made because I *genuinely* lacked insight.”

But what they went on to say, unless I'm conflating it, but I don't think I am, because there was lot of information, was that they actually have no recollection of that period. And there's no record of it. Because they wanted to be reminded, once they'd reached a level of, again air quotes, “recovery”, they knew there was this chunk of time where they genuinely couldn't make the right decision for themselves. They needed somebody else. They needed

other people around them to make decisions in their best interests, because they didn't have the insight to make the decisions for themselves.

Going through that process, they came to another point, which was, "I know that happened, but I don't remember how it happened." And when they went back to say, "I would like to understand that period of time" there was nothing. There was seemingly no record. They were told there was no record of that period of time. Now, either there's been an almighty screw up, and nobody wrote any notes on this particular person, because it was in an environment where they should have had a written record, or theirs, and again, this particular person kind of said, "I started to question, you know, are they deliberately trying to hide something from me? Does it really not exist? Or is there a reason they're trying to keep it from me?" And that sense of uncertainty is really unhelpful for people, and really unhealthy for people. And that kind of came through, this kind of searching for an answer.

And I as the badge wearer, I as the professional, I should have the answer. I should be able to tell you the conversations we had last week, if I'm supporting you. I should have written it down. If I didn't write it down, and for this particular person, if the team that was supporting them didn't write those things down, that's a serious problem. Because what happens, God forbid, if they're in that situation again, and the past is brought to the future. They then have no argument. You know, if they become unwell again, they were able to say themselves what they were going through, and you know [sighs] if that happens again that they need support, that new team is going to look at the history.

If the history doesn't exist, who gets to tell it? Who gets to tell the truth? Does that new team get to fill in their own blanks because there is no written record? Do they ask the person, the person then says, "I don't actually remember. I needed that record, I needed that written documentation, to tell me what happened to me in that particular moment, because I can't remember. I know it was bad, and I know I needed help, but I don't know what happened to me." How does that new care team, if they need that new care team, move them forward? When all they're trying to do is look back, but it's an empty space. It's a blank space that needs to be filled. And the thing that came to my mind when I read about that experience of that particular person was, who gets to fill in those blanks?

And my concern is it's not the person who gets to fill in those blanks. It's the people who are supposedly supporting them. They get to pick the pieces of history that we do have and build a picture for that particular individual. And we see that all the time. Record keeping is terrible. Particularly on wards, particularly in inpatient teams, record keeping is very, very poor. And there are days where you would read a record and it would be like that person doesn't exist, they apparently did nothing today. Apparently they didn't exist

for a day, because there's nothing written down about them. What happens when someone needs that evidence about that particular day? What if that person knows something not good happened to them on that particular day? Who gets to answer those questions? Who gets to give that information?

And that's all part of that game that we're all playing, as part of this system. And none of us know the rules. And again I'm contradicting myself because earlier I said, “I know the rules”. But actually, on reflection, I'm not sure I know them either. Or maybe I think I know them, but the rules that I'm playing by are different and that's not fair. That potentially gives me an unfair advantage, or a disadvantage. Might give me a disadvantage. I don't know.

Eve
I think it's really interesting you mentioning the scenario where there's an absence of records for someone’s stay in hospital and saying, you know, as if that person didn't exist. And I recall Alex saying, “Because I've had so many different diagnoses…” and, you know I’m paraphrasing, you know “I feel like I don’t exist.”

Anon
He doesn't exist, for that particular moment in time. There is no record. And that's not right. You know, if someone feels that they can't trust, or feels that they can’t trust, their own recollection of something, they rely on us, as professionals, to keep an accurate record. But when do we ever keep an accurate record?

Because I work on a language people that I support don't use. I have words to describe human emotion. I don't write in everyday speak. I write in the language that I've been taught by the environment. And nine times out of ten that doesn't actually describe what the person was going through. It pathologises what the person was going through. It medicalises what the person was going through. But it doesn't tell *their* story.

So even if, and I think that's the interesting thing, Alex was saying that they didn’t exist and that there was an absence of any record. But what unsettles me is that even if there had been a record, it wouldn't have been a true representation of what Alex went through. It would have been an *interpretation*, a clinical picture, a pathologised depiction of what was happening at that time, which isn't a lived experience. It's an *interpretation* of a lived experience.

I'd really love to do an experiment. So I run, you know, activity sessions in my job, and it's all about doing. I'd love to work with someone on a particular thing, get them to write their own notes. I write mine, get them to write theirs, and see how similar or dissimilar they might be.

You know, I get to talk about how somebody engaged and how well or not well they participated, and what they seemed to gain from the thing that I was doing with them. But have I actually got that right? Or have I interpreted it through a different lens. And actually if I can get that person to write it for themselves. And so you'd have, effectively, for every note that was written or every piece of written documentation that you have written by a professional, you'd have a pair, you'd have a sister note, a sister entry from the person themselves. That would be a really cool thing to do.

Eve
Is that doable?

Anon
No. Because apart from anything else getting access to your written documentation is incredibly difficult, *and expensive*. People have to *pay* to get access to their personal information, which just seems fundamentally wrong to me. It will be possible to do on an individual basis, if I didn't tell anyone about it. I could do it as my own little private experiment, but I couldn't formally document it. I don't think I could get somebody to write their own entry on a particular thing, it would have to come through me. But if it comes through me, then it changes. Automatically.

Even if I'm working really hard to write it as they saw it, it's still going to have my slant on it. It’s still going to be changed, or altered, however minutely, by my interpretation, because that's how we are as authors, as authors of our experience, or as authors of other people's experience. It's very difficult to be completely objective. And I would challenge anyone to say that they write clinical entries completely objectively. I don't think it's possible. I don't think you can do it. Because we all have a feeling, we all watch somebody doing something and respond on an emotional level. That's human nature. And I don't believe that you can eradicate that. I don't believe that anyone can genuinely guarantee that that isn't coming in to their clinical documentation.

Eve
You spoke about learning a language by which to interpret certain, you know, activities that people do, decisions they make. Are there words or phrases that you've learned along the way that you dislike?

Anon
So many. So many. [sighs]

Eve
Could you give a list?

Anon

We pathologise human emotion. One of the things I hate the most. So there's one word, there's euthymic. What the hell does that even mean? Well I know what it means, technically. What does that actually mean for a person?

I have one particular person that I work with and I support at the moment who, when he comes into the clinical space when he's in the ward round space, he uses that language back to us. So you ask him, "How are you?" He says, "I'm euthymic today." "That's not what I asked you. I asked you how are you feeling?" And it was only then that I realised how meaningless that word is. How it's a catch-all word for somebody being "stable", and being "even tempered", being "stable"…

Eve
You're doing air quotes. [laughs]

Anon
I'm doing air quotes!

Eve
I just wanna make that apparent. [laughs]

Anon
…That's another one! "Stable in mental state". What does that mean? "Settled in mood". What does that mean? They're phrases, I guess, rather than individual words. But what do they mean? And I try to avoid using them as much as I can, because if I were somebody's relative, or the person, I might not understand what that means. So I try to not use that language. I try to find normal language, everyday language, to say that, if it needs to be said.

So those are a few examples. There are so many, so many clinical terms that we use, you know, "responding to unseen stimuli", what does that mean? I know what it means because I've been told what it means. But what does it look like? It's a word, it's a phrase, that on any given day I probably write 20 times, or I probably would need to write 20 odd times every single day, because of the nature of the work that I do. But it doesn't tell anyone what I actually mean. So I need to rephrase it. And I try to find a different set of words to describe it.

And it's taken for granted that we all as healthcare professionals do the same thing, but I'm not sure we do. Whenever you write something down, imagine the person you're writing about would read it. And I try to do that, as often as I can. Sometimes, I will be honest, you slip and you forget that, and I will admit it. I don't want to admit it, but it happens.

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