

Chapter 16: An Icky Feeling

Anon

So my name is [redacted]. I'm in my mid-30s and I work in mental health services as an occupational therapist. I'm currently sitting at my table in my barn, flat-ish, no it is a barn, which is quite tidy today unlike it's usual state. It's looking pretty tidy, and sun's just going down. And it's quite a nice bright, kind of tea time afternoon. And I'm surrounded by lots of things that have memory and meaning to me in here. It's a small kind of single room space, but I've designed it so that I have spaces for different things.

So where we're currently sitting is my working space, where I get to do all my big thinking. So it feels quite appropriate that's where we're sitting now. And I guess when I look around the room and I see the things that I have here I see my family, and the people that have made the biggest impact in my life, on the walls and in the things that I have.

Eve

Is there anything on the walls, because I can see you've got a lot of watercolour pictures, that you wanted to pick out especially?

Anon

Yeah, so there's a painting that is almost directly in front of me which is of a white rose, which is a watercolour on canvas that was painted by my paternal grandmother. And it was painted on the day I was born. So that's quite significant. She's no longer with us and she always said that the inspiration came when she was waiting in the hospital garden before I was born, on the day that I was born, so it's quite special.

Eve

That's so beautiful. And I do get a sense, coming into your space, that art is very high on the list of things that feel like a priority...

Anon

Yeah, they do. I'm not an artist. I'm not gifted in that way, at all. But I appreciate it. And I need it in my space. And I think I see the world in a sort of artistic way. And if I could draw, or if I could paint, I can see so many things that I would draw and paint. But just can't do it. I've never, never really been gifted enough or had the patience to learn, because it doesn't come naturally to me. So having the art around me just kind of lets me appreciate it without the stress of having to try and do it myself [laughs].

Eve

And can I ask you, firstly, why this project appealed to you?

Anon

It appeals I guess first and foremost, when I first heard about it, on a professional level, making positive changes to the environment that I work within, and the system that I work for. I've known for many years that there are things about that system, which don't fit with maybe my worldview or don't sit particularly well with me and I have always sought to understand why, why they don't sit well with me, what is it about those things that are just feeling uneasy. So I guess when I heard about the project, the application to my work was the first thing that I thought about.

But then when I thought more about it, it was more on a personal level of it being something that was also personally very important to me. Knowing people in my life on a personal level who have been through systems and processes and difficulties and had access to services, for want of a slightly less clinical word, and wanting to make changes for them and just have this conversation. I think it's a conversation that needs to be had on both those levels.

Eve

And where should we begin in our conversation?

Anon

I don't mind!

Eve

Because I can see you've got...

Anon

I got some scribbles!

Eve

You've got a notebook here. I feel like that should be observed, that you've made a lot of notes from various recordings earlier on in this journey. So the big overriding question that I've got in my mind is when you spent time with your fellow co-creators, when you spent time with their words and their stories, what did you hear?

Anon

[deep sigh] I don't know whether this was a positive. My initial feeling was that this was a negative thing. I heard everything I expected to hear. I don't know if that makes sense. But I heard, as a professional, thinking from my clinical world, the people who were speaking about their lived experiences and the themes they raised, none of it surprised me. Which I was really struck by. I was really, *really* struck by the fact that it felt so familiar. Those things felt so familiar to me. And they were themes that I had observed and I guess they fit with what I was saying earlier about things that made me about

systems that made me feel uneasy. They all came out. They were all there. Nothing surprised me. Nothing shocked me. And *that* is in itself a problem. As a person working in that space I should be surprised, and I should be shocked, when I hear people's negative experiences.

But honestly, I expected every single word. And that's a hard thing to sit with actually. And just looking at my notes, desperately trying not to rustle, that's what comes through all of the transcripts. And although journeys were very different, and experiences were very unique to each person, there were themes that sat across each. And they're also things I face every single day as a professional on the other side of the coin. And that doesn't sit well. At all. [long pause] Yeah [soft laugh].

Eve

Do you want to tell me a little bit about what some of those themes are? Shall we have a look at some of those things that came out?

Anon

I mean I've got a mixture of kind of, I picked out key sentences that I read from each person or each pairing around autonomy and decision making. And I've got the word underlined somewhere, wherever it is, *dichotomy*. And I don't know if that's even the right word. But it's the word that came to my mind of people feeling torn between proving that they have this insight that they have to prove that they have, but then being in a situation where they know too much, and they become too knowledgeable about their own experiences. And how healthcare professionals and teams of, you know, mental health teams don't warm to that, and don't like it when you become too knowledgeable. When one becomes too knowledgeable, it becomes a problem.

So finding that really tender balance between being able to prove that you understand enough, and that takes us on to another thing that I'll say in a minute, but not knowing so much that it puts people's backs up. And it starts to irritate the people who are supposedly caring for you. And I guess insight is the thing that comes through, through all of this, which is the point, what does that actually mean? [sighs] What questions are we asking people to have the answers to?

And what really came through was some really specific stuff around treatment, and treatment plans, and people agreeing to the treatment plan that they're on, which treatment plan in these instances seemed to be code for medication. That was the thing that people were mainly treated with. And if they questioned it, or they happened to want to know more, or want to know why they were given these medications, then they were deemed as not having insight.

And that, to me, seems totally backwards. Because if someone's asking to know more, they're wanting to gain an understanding, gain an insight. If they're wanting to find out why, why when you hear what I'm going through, when you hear what my and I use air quotes for this "symptoms" are, are you suggesting I have this treatment? Surely that's me proving to you that I have an insight. And that came through the whole kind of conversation, each of the conversations.

Something really powerful, and I've got down, somebody said, and again, I'm not sure I don't know, which, it's interesting, trying to remember who said what, I guess it doesn't really matter, because they're also similar, "meeting me on my own terms", "meeting me where I am", rather than me having to come to where you are as the badge wearer, as the professional, as the person who's got the answers and holding the key to my recovery. And again, I'm using air quotes for the word "recovery". Actually, you should be meeting me where I am and trying to understand where I'm coming from, and this imbalance of having to prove our understanding.

As a healthcare professional, as a mental health worker, I don't have to prove that to anybody because I wear a badge that tells you, or should tell you, that I know I'm doing. Actually I'm making it up as I go along. A lot of the time. Because every person is different. But I never have to, in that system, there's this idea that we as the people who are working in that system, never have to meet the person where they are, they have to come to us.

Yeah, just how questioning, questioning things equals or equates to, lacking an understanding, lacking an insight into one's own needs and one's own health or one's own difficulties. That stood out massively to me.

It felt as though every kind of argument, or every point that was being made, was almost being countered in the same breath by an opposite. So there was the idea of the diagnoses conversation, you know, is a diagnosis helpful, is it not helpful. And there was some debate within the conversations around how people perceived their diagnoses or whether they found them helpful or not.

There was conversation around needing a framework through which to explain one's experiences. But then that same person went on to say that that framework was then used against them. Once it had been labelled, and they were given that framework through which to understand what they were going through, it was then used as a, almost weaponised against them. Which, again, feels kind of icky. And a bit wrong.

Eve

Can you describe what that ickiness is? What it feels like?

Anon

It's very unsettling. I think it's most unsettling because I'm part of that system. That's the bit that unsettles me. I know, as an individual, the things that those people have been through are things that I try in some way, and this is one of those examples, to challenge. Doing *this* is my way of trying to challenge some of those things.

But I also know that I am part of the system and therefore, in a way, I'm part of what's wrong with the system. It's an internal ickyness. It's like it makes me feel, you know, by being in that system, and by working within those boundaries, and within those values, I'm perpetuating these issues and these problems, even though I know on a day to day basis I try to challenge them as much as I can. I don't know if that helps explain what I mean by icky but it just, just doesn't sit well.

Eve

And what does it feel like being part of a system that feels icky, that gives you an icky feeling, and trying to push back and trying to challenge it? What is that process like for you?

Anon

It's quite a heavy process. And it's a daily process. And I think it's about finding, I'm very conscious of finding, opportunities to safely push back, you know, because it's my job, it's my career. And that's always in the back of my mind. It's something I want to continue doing. My job is incredibly important to me, but I want to be able to push back at the things that don't fit with my view, that don't fit with my perception.

So just finding ways in everyday, and you know not making a huge fuss about it, because I find that the people who, particularly the professionals, who stand up and make a fuss and shout the loudest tend to be battered down. It's about very gently, as often as I can, just dropping in a few counter arguments, very respectfully, with my colleagues and with my peers and with other professional groups.

Just always being mindful that I'm there as an advocate. I'm not an advocate, and I recognise advocates are their own role, and I wouldn't wish to step within that role, but at the same time I do feel that I should be there as an advocate. And so just gently dropping those counter arguments in wherever possible, as often as possible, is how I try to do it. Because I find that's how you're best heard.

I think we live in a society where, whatever sector you're in, the people that stand up and shout and protest and make a noise, actually are the people that get ignored, which they shouldn't, that shouldn't be the way, so it's about doing it quietly and doing it subtly.

Eve

Obviously we need to be really respectful of confidentiality and other people you've worked with and their confidentiality. I wonder, is there a safe example of this? Without mentioning any specific details, but a kind of broad brushstrokes overview of a situation that you might challenge?

Anon

That's a surprisingly difficult question [sighs]. There are specific examples, but it's finding the best way to articulate them.

I suppose a common forum for the conversation is within ward round. So within the clinical space, where the whole of the care team meets the person that they're caring for once a week. That's probably the space where the conversation happens the most. And it may be just reinforcing an idea, or, I can't think of a specific example.

Eve

It's a difficult one, isn't it? Because with this kind of a process, we're treading quite a line where there can't be too many specific details around individual people you're working with, or scenarios. But would you challenge a situation where someone was vocally requesting either a reduction or wanting to withdraw from their medication? Would that be a scenario where you would challenge...

Anon

That's a really interesting scenario, because I have to be acutely aware that I can never, as a member of the care team, advocate for someone not taking something that they're prescribed. I cannot do it. If I do it, I lose my job. It's that simple.

But actually, there was a situation relatively recently that I could probably bring in, where somebody was saying there are too many tablets. There are just too many, the quantity. They weren't arguing what they were taking, they were arguing how much. Not even the dose, just physically how many tablets they were taking. And that was originally dismissed as well, "There's nothing we can do about it". You know, "That is how many you have". End of discussion. And with the little bit of knowledge I have around pharmacology I sort of said, "Is there not a way we could reduce them?" You know, "Could something be consolidated? Could doses be consolidated rather than split?"

It's not a very good example, because actually medication isn't my expertise I suppose. It's not the bit that I know about the best the most. But yeah, I was able to open a conversation for someone to sort of say, "I'm just taking too many in one go. And I don't like it." And so, you know, "Would they would they be able to have something in a liquid form, as opposed to in a tablet form?"

Just enabling a discussion, even if the answer is no, and I guess that's the other thing, even if ultimately the answer is, "We can't change anything" we have a duty to try and meet somebody's request. Even if by the time we've gone through all the options, and we've talked about it as a team with the person, we come to the kind of realisation that actually there is nothing we can change, we have a duty to give it a go. And that's the bit that I try to advocate for. Just allowing a space for seeing if there's a different way, seeing if there's another approach that can be taken.

I guess another example of the ickyness [laughs], when people first come to, so it's a ward, so people stay with us, when people first come to the ward, the protocol and the policy dictates that they can't be given their leave from the unit straightaway. Despite, you know, no matter where they've come from, what their situation was previously, it's because we need you to adjust to this new environment, that's potentially a risky situation, so the protocol is nobody gets to have time off the ward until we decide it's OK. That doesn't sit very well with me.

Because what happens is, by the time someone then is given the opportunity to go out, they've usually already started taking medication. And to me it should be the other way around. It should be, let's allow you the opportunity to develop that routine, as an OT that's a huge thing for me, develop that routine, become accustomed to the environment, work out what's important for you, what helps you, does a walk in morning help you, does fresh air at a certain time in the day help you, what are particular activities you might enjoy, and then we can consider the pharmacological stuff.

I don't ever want the pharmacology to come first. Because I don't think that's helpful. And so there have been many times when I've advocated and I've said, actually, this person for the last five years has been living in their own home, having open access to their community, with no issue. We have no reason to think that they won't cope going to the garden. So can we just let them do that? Can we support them to do that as soon as they arrive? And *then* consider what the treatment needs to be?

Because nine times out of ten I find, and this is one of the things that doesn't sit well, if you restrict somebody's movements whatever they're struggling with will get worse.

Bethlem
Gallery



Backing
Better
Mental
Health.

NHS
South London
and Maudsley
NHS Foundation Trust

