

Chapter 5: Sitting in the Pain

Eve

You've mentioned, a few times it's come up, this word insight.

Ninette

Mmm hmm. Insight.

Eve

Yeah, that I've been trying to investigate, and get to the bottom of, for about two and a half years. [laughs]

Ninette

Oh gosh! [laughs]

Eve

And the further I go, the deeper I go, the farther away I feel from any kind of conclusion, resolution, whatever you want to call it. I don't know where I'm going with it. I feel like I've fallen down a bottomless well or something.

Ninette

Yeah, gosh, I mean, I can totally understand what you're coming, where you're coming from on this one. Because it's like, insight to me, if I just wanted to dial down and keep, like, my understanding of it super basic, insight, essentially, is context, is it not?

And you can never have too much context. It's like context is the information, information surrounding something. And there's infinite amount of information and context. If you want to see the contextual side of things. Or if you want to just take things at face value, which, how do you learn anything from just how something appears on the outside?

You have to probe, you have to investigate further, in order to understand, but then also having context doesn't, or insight, more so, doesn't necessarily mean that you understand anything at all, though, does it? [laughs] You could literally be, you could have X amount of insight, but know nothing at all. It's a very odd one.

Insight in the light of the things that we're talking about, had I had the insight into how the police officer was going to treat me I wouldn't have called, had I had insight that, after being sectioned that I would end up working for the same people that failed me, would I would I've still taken the same steps if I knew this was how it's going to end up? Dunno [laughs]. I just don't know.

It'd be too easy for me to sit down and say, "Oh yes, I'd do it all again". I'd probably do something different, but ultimately I am where I'm supposed to be. The things that happened are supposed to happen. It's my approach to what has happened to me that matters the most. As opposed to the thing itself, sometimes, you know? If I focus on what has happened to me, and the failings, the negative side of it, I probably wouldn't get out of bed.

But it's more about what I decide to take away from the experience. And I decide to take away the fact that there's room for improvement here. There's space for me to utilise this experience to help improve things. And that's the underlining, flashing [makes siren noise] siren at the end of the day. I can choose to use this experience to help other people. And that has been like a key force in me doing the work that I do in peer support. It literally is my saving grace to a certain degree. Literally.

I get such a buzz off helping other people. I get a buzz off when somebody is able to be brave to share a personal experience that's super dark and scary, because not everyone has or feels that they can, talk about some of like the most haunting things that they have going around in their mind, you know?

I've been there before. I've been there, you know? So I think there's something very beautiful in sharing in your experience. Because a problem shared is a problem halved, it is true. Once you start talking about it you're en route to finding the solution. You are.

Eve

[both laugh] There's again, there's so many things going through my mind as you're talking. I was wondering when you were talking about, you know, had I had the insight into how I'd be treated I wouldn't have done that, for instance? So you're, you're talking very much about the insight that you have and the sense of the word from your own understanding. And I'm interested also in the ways that the more clinical understanding of insight can vary quite a lot from individuals' sense of insight. Like you mentioned context being a way to understand what insight is. What's your sense, or understanding, of how clinicians think about insight?

Ninette

Mmmm, interesting question. I feel that, in regards to insight and clinicians, and, again, this is very general, I think that not enough emphasis sometimes, on the clinician's part, is placed on insight aka what I would paraphrase as context. I feel that it's too easy, for example, being a clinician with somebody that's presenting as having mental health issues, it's too easy to sort of go about things with the textbook approach. It's too restrictive. I feel that there's a person behind the bloody diagnosis!

So if you get to know the person, and what they've been through, insight, then it's going to help in understanding why a person is presenting with mental health issues. I don't think that the clinicians in general put enough emphasis around the individual person. I think people are just grouped together in terms of behaviours and things. But there's more to people than their behaviours. There's more to a person.

So I feel like, all in all, not to knock what clinicians do, that's definitely not my intention here. I think more, if anything, the point that I'm trying to make is a clinician obviously has a place, people find diagnosis and the wealth of information that clinicians have super important, but it's lacking in terms of like the human touch. The human approach.

Which is where peer support comes into things and balances out the sort of mental health landscape. If we're talking like hospitals or, you know, wellbeing centres. There's definitely a space, and a definite need, for clinicians and peer support workers to co-exist. I think that's an award winning duo right there, to be honest with you, you know?

And also, in the same breath, it's like peer support workers aren't perfect, like we're not made out of gold, we also benefit from the insight that clinicians have to offer because of course they've got information that we don't, you know, that we may not have taken into consideration. So, if we work together and combine all of our insight the more people we can help [laughs].

Eve

I suppose one of the risks in these kinds of clinical environments is people being grouped together, seen in a certain way, under a certain kind of umbrella. Were you grouped in a certain way?

Ninette

Oh, absolutely. You know, I'm grouped on a daily basis. But if we're talking specifics, I was grouped, or they attempted to group me, or put me into the box of, The Angry Black Woman Whose Lost It. That box. But I don't belong in that box, or any other box for that matter. It's just too restrictive for such a broad, liberated mind like mine. You just can't categorise people like that. And then make ill informed judgments on your preconceptions that aren't even correct. You're endangering people. You're endangering people's health. You're endangering care. It's like, let's do better than this.

There's, and this is the thing, OK, I will try my best to stick to the plan as best as I can, because it's like one thing always leads to the next because everything is connected, isn't it? There's no space for judgement in the healthcare environment. There's no room for it. And we really need to work to minimise and quash it all together. Because we're talking health.

You can't go out and buy new, like, a new improved version of your health. It's something that needs to be worked at. It's something that literally is ongoing. It requires, well, it requires like, review. It requires like, constant work, but not work in the sense of something that, that feels difficult. It should be easy. And it's easy with the right people, you know?

Eve

I'm really really interested as you speak, I'm interested in the fine mechanics of the specific kind of racism that you're talking about. And misogyny, basically [both laugh]. I'm trying to figure out how this operates, how this has worked, how you've been seen in this way and labelled in this way.

Ninette

This is the thing though, isn't it Eve? In terms of a question like this, is this not better posed to those that actually specialise in that type of behaviour and treatment? Because I don't know what their motivators are. I don't know why some people believe, for example, a Black woman is angry all the time. Like, where does that come from? And truth be told, we've got every right to be angry, from being, you know, judged as soon as you walk into a place for just being Black, for example.

So, OK, let's talk about the sectioning, if it was, OK see that's dangerous territory because we're going into like something fictitious here. But then again, maybe that would help drive the point home. If it was a white lady, like yourself, in the situation that I was in, a family dispute, you called the police for assistance, and let's say you got angry as a result of what was going on, which most humans would, do you think that the police would have handled you like that? It's difficult to say, isn't it? But we both know the truth is no they wouldn't have.

Because, it's like, this lack of respect has come from aeons ago. I'm somebody whose just happens to be a human living in the world, and just wants to be treated fairly. I didn't choose my colour, the colour of my skin, but I love it. And no one's going to make me feel a way for enjoying the fact that I'm Black. Why can I not enjoy the fact that I'm Black and a woman, and I'm all right as an individual? Why do I have to be penalised for that?

Like I'm not penalising anyone else, for example, for having a dick. Like, I don't care what you've got, in terms of like, what you're wearing or, it's about your heart, show me your heart. That's all I'm concerned about. And my heart is OK, again, I have to keep on saying I'm not perfect, but I'm definitely not an arsehole. So I don't deserve arsehole behaviour on account of somebody that has preconceptions about me that are not true. And as a result is going to treat me unjustly. It just doesn't make sense to me.

So although it's a super awesome question, it's a question that needs to be posed to people, for example, that are in the police force and working with these judgmental beliefs which affects work and affects the wider community and people like myself. We need to be asking them why they're behaving like that. Why are you doing that? Like what inspires your behaviour? Like, where does it come from? I'd like to know. But I honestly cannot answer that question.

Eve

Yeah, yeah. And as you're talking I keep coming back to the image that you shared earlier, where you're talking about putting the blinds down, the shutters down on the window and then a blanket on top of it, and just turning away from the outside world. And I can't imagine any other response. If I had been in that situation I wouldn't know how to pick myself up. You talked a lot about learning how to love yourself and move through that shame that you felt.

Ninette

Because essentially, after that experience, I was of the mindset that, OK this has happened because I probably am mad. But yeah, of course I'm mad. I'm mad because something completely unfair has happened to me. Of course I'm going to be mad about that. How could I not?

It's just yeah, it's actually mind blowing that this seems to be, it's almost like it's commonplace, like it's common practice that people are treated like this. And I mean, not everyone is going to have like, a story similar to mine, where they're able to see the light at the end of the tunnel, let's talk about the people that just are not seeing any light anymore, because of this unfair racial treatment. How about those people that, like, what I was doing before in terms of pulling blinds down and putting an extra sheet on, that's their reality right now, you know? That's proper sad.

And that's why I feel, not even obliged, I feel like my service to the world is helping those people lift up the blinds and see the light. Because there is. It's pretty shit sometimes, in terms of like, how the world works, and the fact that there are people that will go out of their way out of hate to treat other people differently. But at the end of the day, that's not, that's a microcosm of society. Like that's one slice of the pie.

There are other people that make the world more colourful and more enriching. Like a nice place to be. That's what needs to be focused on. But we can't forget the fact that there are, there is, there is a small section of society that really needs to reevaluate and innovate their thinking. It just doesn't work.

Eve

What is the insight, the genuine insight, your definition of insight, that's really needed do you feel?

Ninette

Insight in terms of what's needed with mental health?

Eve

To get the kind of change that you're describing?

Ninette

Honestly, I think it will be an individual and collective movement. Until people are honest, are able to honestly take a look at themselves and their behaviours, on a scale of just and unjust, then a lot of things aren't going to move forward.

And I think a lot of people struggle to look honestly at themselves and the way that they conduct themselves. But it doesn't mean to say everyone's that way inclined. Some people actually thrive and, you know, look into self-improvement, self-development, self-growth, so there is hope.

I think it's almost like those people that thrive off knowledge and insight kind of need to surround the people that completely just overlook insight. And maybe we just need to infect them with like this need to know, like this pursuit of knowledge. I don't know [laughs]. It's gonna take a lot of conversations, to say the least.

Eve

And you're already doing it with the work you're doing in the NHS and the peer support work.

Ninette

We're doing it right now! [laughs]

Eve

What's it been like for you going into hospital environments, given the experience you've had within them?

Ninette

It's going to sound so odd, but I kind of knew because I'm someone that if I feel uncomfortable, sometimes I will shy away from things. Typical human nature, isn't it?

So after I was discharged from hospital, I made a point of going back to the hospital so that it would minimise any discomfort that I had. So literally, I was putting myself into uncomfortable situations because I don't want to be scared of being in a hospital because of what's happened. I don't want to be

fearful of anything. At the end of the day it's a hospital, they should be there to help.

However, it was a traumatic experience being there. But I think me working on the wards now is such a breeze because of these uncomfortable situations that I put myself into, you know? I just don't feel that with everything that's happened to me there's any room for fear. Of course I get scared of menial things, but on a grand scale I just feel that fear is so debilitating it can stop you from actually living. That's, that's what I went through after that scenario. And I just can't see myself ever going back there. It's just not where I want to be. So in light of that, I just feel that if something's going to make me uncomfortable, then that's where I need to be. [laughs]

Eve

It's just amazing, that process of taking yourself back there. Like really looking directly at the place, and the thing, and the pain of it.

Ninette

And just sitting in it, you know? There's something quite poignant in sitting in pain. Because essentially, pain is temporary. It has to pass at one point. And I feel that, perhaps maybe in my younger days, I spent a lot of time running away from things that felt difficult or were uncomfortable.

But I feel that there's a, there's a lot more to be gained and learnt from just sitting in the pain [laughs]. Like, it's OK. Like, pain is sometimes that's a reality. But that isn't the entire reality. It's just part of it. I don't know. Sounds like I'm super wise and I know what I'm talking about. But literally the topic matter is me and my experience.

I think sitting in the pain in some ways is like, accepting what has happened to a certain degree. Because I couldn't turn back time and I couldn't change. I think a key thing for me, why I was blaming myself, is because I feel that if I had found a way to minimise or, you know, condense how I felt that day, then maybe things wouldn't have gone that way.

But then I'd be changing who I am as a person to fit other people, or to make them feel more comfortable. So again, there's no place for that. I don't know how to explain, I know I'm going down like a meander of different things here, but sitting in the pain is, I guess in some ways I've become accustomed to doing that. Yeah, truth be told, I feel like I've just become a bit accustomed to pain. That's not really, umm, is that true though? I think, yeah that's another one, I'm actually literally like is that true? Well, [laughs] you're actually Eve creating some thought provoking questions here! And I'm like, wow, OK is

that really how I feel about it? I think it's necessary in order to appreciate things in general.

Eve

I guess with this whole process of trying to bring people together to have chats about justice and injustice, and insight and what it means, [sirens blare outside] what it looks like, all of these tensions and these challenges and abuses that do occur, that are occurring, that are occurring now, as you say I think I've always felt very aware that there are people that I'm not reaching as part of this process. People like you were describing, feeling very isolated, with the curtains drawn, and I'm really aware that there are stories that we just don't hear. And that's painful.

Ninette

It is. Like literally I felt something go off in my heart there. Imagine that? There are, and, yeah, there are people out there that need to conversate. How do we get to draw them out? How do we find them? How do we support them? Because they're still going through the process of even conjuring up the energy or whatever you want to call it to even speak on their experiences.

Because that takes a lot, to be able to talk about something that is really troubling and, well in the same breath, really close to your heart, isn't it? But we have to. We have to find a way through that uncomfortability to talk about stuff like this. But first and foremost, people need to be given the, not platform per se, but more space. Like the arena to just voice whatever's on their mind. So important.

Eve

And I'm also thinking about what creates that platform. The safety that needs to be physically built into it, emotionally, psychically built into that arena, that space.

Ninette

Trust is a key component. The ability to feel like, you know, whatever you say, or whatever it is you're feeling that it's not going to leave the space or it isn't going to be used against you, or, yeah. Trust in others, which is a big, that's a big deal. To, not everybody's got that capacity or tenacity to do that.

Yeah, more thought provoking questions. How do we reach these people? How do we get them to talk? You can't force anyone to do anything, isn't it? But they need to, it's not even, we're not even at that stage. We're at the stage of even just finding where these people are. Just literally finding them.

Yeah, there's a lot of work to be done. And I feel like more people like yourself that are dedicated to giving people or creating that space for people to, to voice their stories. Yeah, that's part of the process. We all should play a part in helping other people to express themselves [sirens wail in the background, Ninette laughs]. Yeah they're constantly there! It's like they know what we're doing. They're just like, yeah, we're just gonna put the sirens on [laughs]. Oh, gosh! [sirens continue loudly]

Eve

Where are we at time-wise? I'm just trying to check.

Ninette

Did you have a specific time in mind?

Eve

No, no, yeah I'm open to [sirens get louder] on my gosh that is quite...

Ninette

It's ridiculous isn't it? It's like they're in the room.

Eve

Yeah they kind of are, in the chat.

Ninette

They are! [laughs] They actually are. Insight, hmm. Is insight actually helpful though? [both laugh] Literally.

Eve

We're both just looking at each other like...

Ninette

...is it? [laughs]

Eve

I guess one way of opening that out, because that question I've been asking myself a lot through this process is, is it a useful clinical concept? And then, is it useful in terms of the way individuals conceptualise insight?

And there's so so many different ways that people have described to me, even during the research phase of the project, which was about a year, year and a half of having conversations with people about what is this thing called insight, and how should I go about exploring it? What does that even look like? What does that process entail?

There's been so many different definitions of insight, from a personal perspective, that I've actually lost count the number of interpretations from a

more embodied, individual perspective. But what I'm coming up against is these personal definitions they don't match the clinical understanding of insight.

Ninette

Which must create some sort of friction, you know?

Eve

Yeah.

Ninette

But in the clinical sense if we're talking insight should there... but that's the issue with blanket terms or just one, I don't know I feel like that could be quite troublesome in itself. Clinicians that just have one blanket approach to insight. Because insight's too broad for that. Yeah, I'm actually creating more questions rather than answering the questions.

Eve

I think that's important. It feels an important part of the process to ask more than we can answer.

Ninette

Absolutely, because I'm super curious. It's literally such a conundrum. But I love this. I love that. I just feel that it's ultimately problematic to have one set definition for anything. Because it's almost like that sort of theory of trying to group and put people into boxes, which I super am against.

So maybe it's actually better that everyone has a different perception of insight? They're bound to have different perceptions, because everyone sees things differently. And there's no problem with that. It's important for us to just understand each other. And I guess we, we can only really do that through conversation and communication.

Eve

I'm wondering this, were you ever involved in conversations with your clinical team, or even the police might have been involved in this, about insight? Did you ever have any conversation about it during that period?

Ninette

No! None at all. And the thing is, I feel that if it was in, in the sense of the people that were involved in my quote unquote care, it's like they were talking about me and not really communicating to me. So it's almost like I'm the third wheel in conversations about my care. Which doesn't make any sense.

But again, I really do feel the judgments that I felt based on my colour and my sex all play a part in that. Because it's almost like as a Black woman I've been written off. So I don't deserve to take part in a conversation about me. Like, that's how severe this situation is. The discrimination that I'm talking about is literally on that scale, you know? Which is absurd [laughs]. That is crazy. That's mad. And treating people like that isn't going to help anything, you know? It doesn't help anything at all.

So it really does take, that's why, I don't know how quite to explain this, but where I'm drumming at or where I'm going out with this is basically the fact that that's why it's important to know oneself and to take care of oneself. Because on the back of insight, a key thing that the clinicians, the police, all of this stuff, all of the people involved, did not take into consideration or bear insight to the fact that I'm anaemic. So if you're going to keep me in a police station for 24 hours, no food, no water, having panic attacks, of course it's going to cause a mental health concern. Of course emotions are going to go through the roof.

And it's like, but this is basic information. Why would you think that treating a person unjustly is going to have a positive return? Why do people think like that? That's what I'm interested in. That's what I'm curious about. Where does this come from? Like, where does this thinking come from? Where does this judgmental thing come from? Once we can figure out where it's come from, then we can start working towards a problem, sorry a solution! Not more problems! Solutions! [laughs]

Eve

Absolutely. It just sounds like from the whole of your experience, from the moment that you called the police for assistance, to winding up in that hospital against your will, not permitted to leave, there was no one seeing you. There was no one empathising with where you were at. It sounds. That's the feeling I get when you're talking about it is, who's caring? To be left alone for 24 hours without food or water in a police cell...

Ninette

Yeah it's horrendous! But there are people that have been in that situation, I'm sorry, it's like I literally have to take myself out of the situation and remember the fact that other people have been in those situations and they don't even walk out of the police station. They are carried out into a crematorium because they're dead. Because that's what some police people do.

This, seriously we need to have a look at what is going on, a review of the police's approach to anything that has an essence of mental health. Actually, overall it's not, this issue's bigger than how the police are behaving in mental health related situations it's actually we need to review what are they doing

all in all. Because if you can't seem to behave appropriately in a situation that has an essence of mental health related to it how on earth in general are you able to serve the public overall?

I feel like the people need to look into the misconduct of the police. But we know what they're doing; it's like what are we going to do about it now? Again, this is where I feel like the power of people and community comes into the mix. I feel that if we stand together and we keep on talking about these things that are not working, eventually the powers that be will have to work on changing it. And if they don't work on changing it, then maybe we need to find a way of changing it ourselves. I don't know how that would look like, what that would feel like. But I really feel that there's power in people. We have a lot more power than we think, when we stand together.

Eve

When you made that call, asking for them to help you...

Ninette

I gave them the insight. I gave them the context, FYI.

Eve

Yeah. When you were trying to get help to navigate a really, really difficult interpersonal situation, what did you want to feel?

Ninette

Supported. Just support. And that's literally the key reason why I called them. Because my belief, previously, is that if I am in a position that warrants support, then I should be able to call the police [loud sirens wailing outside]. But then, again, this situation has showed me, has showed a key reason why a lot of people do not bother calling the police. Because ultimately [laughs, sirens continue], ultimately, the treatment that I've outlined is what they stand to be treated like. Who wants to be treated like that?

That's why people just take a lot of situations into their own hands, because involving the police can sometimes lead to unnecessary situations, i.e. sectioning. Why would you, why would you put yourself into that situation? Which is sad, again, because we're paying tax. And one of the things that comes under tax is police, right? So what is it that we're actually paying for here? Because I feel a bit shortchanged. You just have to work on it.

It's very, see this is the thing, all right, I'm gonna, I'll say this, because I feel like it's too easy to sit down and complain about things that don't work alone. And I think to a certain degree, yes, everybody needs to vent, yeah get it off your chest, but where it becomes unproductive is when you're just complaining for the sake of complaining, and you're not doing anything to

help remedy the situation, which is why I'm super like, I feel super blessed that I'm even involved in this project.

Because I like what you were saying about opening up the conversation, sharing this with the people concerned, the people involved in the NHS, the police, and seeing what we can do. So it's more than a conversation now. It's a conversation that's going to hopefully be followed with action. And that's what's needed. More talking, of course, but more action too, you know?

Eve

Yeah. I want to see concrete stuff come out of this. Yes, it's an art project, it's about research and arts, but I really want to see change on the ground. And I think there's something about that combo of arts and research that can potentially do that, under the right conditions.

Ninette

Yeah absolutely Eve. And art is so powerful. And I love what you said, you were so humble with it, you're like it's just an art project. But you and I know it's more than art, isn't it? Art has the capability to completely spin the brain around and [claps hands] change our lens on the world. That's how powerful art is. So yeah, it's definitely more than an art project [laughs]. You know that [laughs]. You know.

I think the greatest thing that we can do, in the type of work that we're doing, is give someone time. Time, and your ear. Well, ears plural. But yeah, time, and to actually listen. I think we talked, we briefly touched upon listening, or, I was having a conversation with someone yesterday about listening. Because she's saying, "Hmm, yeah, well, you're listening to me right now" But are you, really listening? Am I really listening to you when you're talking? Or, am I picking up on something that is relevant to me with the view to focus on that particular point? Like waiting to respond to listening?

Because active listening is an art. Literally. It's an art form. The practice of *literally* focusing on the word someone's saying, and just literally focusing on that alone. It's a lot difficult than most think, you know? But it's not impossible [laughs]. Definitely isn't impossible. So like, going back to the point that we were touching on, in terms of what we can do to help others, definitely time and space. And listening.

