

Chapter 3: Talking to a Brick Wall

Hattie

[crashing sound] Oh shit! Sorry.

I've balanced my phone really precariously, because it's right next to the microphone there's going to be such a loud crash where that fell over!

Um, OK [laughs] [shuffling sounds as Hattie rearranges their microphone]

Helen

Yeah my tripod's balanced on my stuff. I've got my books, like a jigsaw puzzle, it's sort of precariously, well not too precarious, but yeah, what you were saying just before we finished about sort of always being told to reach out, and then when you do you find that no one's got time for you, or they say, "Why have you asked for help? You need to deal with it yourself." And that's what's happened to me quite a lot.

So even just recently for example, I've been trying to, in my team they say, "Oh we're always here. Contact us." And I do, and the person whose been assigned to my care, she doesn't really reply to my emails. Doesn't even read them properly, really. And I only see her once a month, which is just not really useful.

And so you spend a month and you build up all the things you want to talk about, and then it comes out into these appointments and they'll act as if I'm asking too much, as if I've got, you know, as if there was a problem with my expectations.

They were all you know, "We can't read your emails. We can't answer emails. We've got a full caseload." And it's like, "But I'm *on* your caseload!" And that feeds into wider issues around staffing and resources, and actually I don't think this is very safe.

It's this thing where I try to reach out and then you don't respond to me. And it's like when they ask me, "What do you need?" And I say, "Well this is what I need." And then they say, "No no no." And I'm like, "Well, I'm just not going to tell you anymore." And then they say, "Helen you've got to tell us what you need, you haven't told us."

And I'm like, "Yeah I have, but there's actually no point anymore." Like, I don't see the point telling them what I need, because all I get is a "no" all the time. If you can't provide me with what I need, I don't really see the point in asking in vain.

Hattie

Yeah it's just more painful. It's like talking to a brick wall.

Helen

It is! You're exactly right! It's like talking to a brick wall, genuinely, because you're talking and it just makes no difference.

And this narrative of like, just ask for help. I just think sometimes have these people ever tried actually asking for help? Because you ask for help and you get told there is no help, or you're just passed around and no one knows what to do, and you're just told to take responsibility.

Hattie

I totally feel like often you are kind of just being passed around between people.

There was quite a long time where I'd sort of asked for help and was put on a really long waiting list and always told, "You don't meet the criteria for this service". And then we tried to look into private options at the time and then all of the private therapists were saying, "Oh no you're too complex for us. You're too high risk. You're too difficult for us to manage."

And so I was just falling between half the people being like, "Oh, you're not ill enough, you don't meet the criteria for this service". And then the other half being like, "Oh no, you're too mad, we can't deal with you".

Helen

Yeah it reminds me, I don't know if you've seen online floating around this Venn diagram where it's like, you're either too mad, you're not mad enough, and then there's like just the right amount.

Hattie

Yep! [laughs]

Helen

I agree with this idea of slipping between the cracks.

Because at the moment, for example, everyone's just saying to me, "Oh, autism, that's not our remit, not our remit". You know, "We don't deal with that. Not our responsibility". And it's just like, well whose remit is it then? It's very very difficult to get support. And everyone is very keen to say, "Well, it's nothing to do with us". And I say, "But it's actually something to do with you".

You know I got a diagnostic report, but beyond that I didn't get anything. I would have appreciated having a bit of a chat afterwards to know what the avenues for support are like, but you're very much left to deal with it.

And I think, because they see me as *high functioning*, which don't even get me started! [laughs]

Hattie

Oh my God!

Helen

You know, everyone's just kind of saying, "It's not our responsibility".

And I just think everyone seems to work in these independent little silos, in their own territory, and they're desperate to keep anyone else out. And I just think sometimes, like my God, can you people actually communicate?

It's really funny because there have been times when I've been in A&E, have spoken to psych liaison and they've said, "We're gonna contact the eating disorders team." Now, psych liaison and the eating disorders team are in the same building. Psych liaison is on the ground floor and the ward is on the floor above. And there have been times when there's been no communication, and I just think, oh my God you're literally in the same building. Can someone just walk up the stairs please? [laughs]

Hattie

It's not that difficult.

Helen

I just think it's absurd. Or how they don't have, they seem to have different systems for people's notes. So sometimes they say to me, "Oh, I can see from your notes that X Y, Z." I was like, well, that's just not true. Like, I don't know where they get their stuff from.

So you end up with nobody really taking responsibility and everyone else saying, "I'll refer you to this person, they'll get back in touch with you." No one contacts you. You have to then chase them up, which is not really our responsibility.

I remember once, I think I was on a medical ward, or in A&E, and I remember one of the nurses said, "It's quite clear that something has really gone really wrong here with your care."

The fact that I would keep ending up in same situation, but there'd be no follow up. And it would just repeat, repeat, repeat. And everyone was just kind of keen to be like, "Nope, we won't deal with her."

Earlier this year things reached a new low and again I was in A&E and had an assessment with psych liaison and they were like, "Oh we're gonna refer you to the CMHT". And then they just said, "Oh she's displaying personality traits", or "traits of BPD", and I thought, oh my God, "So we want to refer you to the PD team". And I thought, of course, you know? Even though I said to them it's not a route that I want to go down. I explained to them why I didn't meet the criteria.

And it was like tying in to that idea of insight, they couldn't cope with seeing someone, a seemingly rational person, acting in very irrational ways. It didn't compute. They couldn't understand that I could do things and talk very rationally and matter of factly on the one hand, whilst being in quite dire situations.

Hattie

I feel like services do tend to lose their minds a bit when someone has more than one diagnosis or more than one area that is difficult. They're like, "We're not here for OCD, that's a different team. And this is a different team." You know, we can't deal with someone who's autistic and has an eating disorder.

They want to chop you up into little pieces and get different teams to deal with different bits as if the OCD is any separate to the eating disorder, you know. You can't understand them without looking at the full picture, but everything's with a different team. And like you say, they don't communicate with each other, or the notes are on different systems, so they can't access them.

So I was in the acute ward and they were trying to do the referral to the supposedly specialist PD ward it took quite a long time because they wouldn't take me because I'd had an eating disorder. And I said, "I'm not struggling with my eating disorder right now". And also, that's not separate to any of the other things that I find difficult. I have a whole shitload of different diagnosis-is, but I don't identify with most of them. But like, they're not separate experiences. And I don't think that people can try and understand them separately.

But that was really frustrating when they were saying like, "No, because you have an eating disorder." And I was like, "Well I did". And I had lost weight, but that was because I was vegan and they didn't have any vegan food so I didn't have anything to eat. So it wasn't my fault. [laughs] It's so frustrating when you're just trying to explain the experience, but they're like, "Oh, we don't deal with that".

Helen

And I think it's interesting as well how they were, the eating disorders team, were like, "Oh, we can refer you to the PD team. No problem." And I was like, "No, I'm not going down that route". I did not want to let myself have that label. It was about self-preservation.

So they're very willing to refer people, and they were like, "We work very closely with that team". But as soon as it comes to autism it's like, "Oh we don't want to deal with that", "We can't deal with this", "We don't work with this".

It's interesting isn't it, how certain diagnoses are sort of, the PD label is very tricky because on the one hand it can be an excuse to be treated like shit, but on the other hand there are certain doors that can open.

For example, there's this specialist PD hospital in London for *severe and intractable PDs*, which [laughs] don't even get me started on that! But they've got inclusion criteria and exclusion criteria, a whole list of them, and likewise, like they've got to be my criteria, and you just think, well who are you actually accepting? You just think, well what if someone needs that kind of treatment, you can't just label them with a, for example, PD label.

And when they were talking about referring me to the PD team, because they were mainly doing it because they said, your level of risk. And I said, "Well, why are you equating risk with PD?" Just because I'm a young woman whose ended up in crisis, why do you automatically think PD?" You know, why can they not accept that you can actually self-harm, be suicidal, with other diagnoses?

And I know some people just get that label not because it fits them, but because it will help them to access a specific kind of treatment. But having said that, I'm aware that it's still not a label that I want anywhere near me.

Hattie

Yeah I mean it's just the label that you get dumped with if you're the *difficult* patient and they don't know what else to say.

Helen

Yeah it's very, almost blaming. It's like, we don't know how to deal with you so we're gonna give you a label, instead of, we don't know how to deal with this because maybe we don't have the skill set, or maybe we're not the right service.

Someone said to me, “Helen, the autism diagnosis, you see it as the reason they don’t understand you, but they see it as the reason you don’t understand them”, which I think is really useful.

I’d hoped it would help them to understand me and for them to work with me. Like I’m trying to help them to help me. But it just seems to be used as a reason to sort of, not exclude, but sort of, definitely kind of just not do anything, because they can just claim, “It’s not our remit”.

Hattie

Mmm, it’s a convenient excuse, right?

Helen

Yeah, exactly! And I’ve said to them multiple times, I said, “Look, I’m not really interested in your transformation plans if you’re not going to really, I think you really need to pay attention to the kind of inequalities that exist in the groups of people who need a different approach, who engage in different ways”.

It just feels like such a huge undertaking, a huge task. And sometimes I just feel incredibly daunted. I just think, well, what is it gonna take for things to change?

I think *they* need to have more insight, to be honest. They’re the ones who need to have more insight, reflect more.

Hattie

Into what it’s like to be on the other side?

Helen

Yeah, yeah.

Hattie

Yeah I totally agree. I think really often people sort of say, “reach out”, and I’m like, “Well have you ever tried to do that? Do you know how difficult it is? Do you know what the waiting times are like? Do you know what it feels like to be told that your personality’s disordered? Do you know what it feels like to be constantly passed between people? And you think twice about telling me that I shouldn’t be upset, and that I should be grateful that there’s services.

Because it’s really frustrating knowing that people are pretending to understand, but they only see it from the one side. And they don’t understand what it feels like to be the person trapped in the system and sort of receiving the care.

Helen

It reminds me of an experience I had a few months ago. I'd sent an email, I had a few questions, I had some physical issues, and I thought, I'll let them know, because they always say, "Oh you've got to let us know." So I emailed them.

And basically, what happened is somehow one of the clinicians who responded to that email, she sent an email to another clinician that unintentionally got forwarded to me, and was basically saying, "Helen's just mentioning this as a way of getting more medical monitoring, she's very care seeking. I don't see any reason to increase it again".

And I was really upset when I saw that, as I'm sure anyone would be. And I remember discussing it with my key worker, and you know it was telling because she said to me, "Helen, I understand, because if I were you I'd be really shocked and really angry, and really upset".

And it's like, if you were in my position, you'd feel the same way. And yet, they don't seem to acknowledge that that's the way I feel. Surely you should treat your patients the way that you'd want to be treated.

Hattie

Mmm, yeah sure.

Helen

I just think sometimes, if they were in my shoes would they really find it acceptable? They act as if they're sort of untouchable. And they go on and on about empowering and responsibility. And I think, if you were in our position, like would you be saying the same things so confidently? It'd be interesting if the tables could turn.

They always talk about, "Oh, we want to empower you by taking positive risks." And well actually, the only thing you're empowering me to do is to harm myself even more. So [laughs] it's actually really disempowering.

Hattie

Yeah, no, totally. Yeah I think sometimes what feels like it's missing sometimes is just any kind of basic compassion. Like trying to understand what it would be like to be on the other side.

I'm probably running out of energy for talking now.

Helen

No, no, it's OK. And I worry I've sort of word-vomited a bit.

Hattie

It feels good to talk about it and let it out, but it's a weird feeling of like, it's nice to talk to someone who, we can relate to each other, but it's also just like well sad to hear the stuff you've been through.

A kind of mixed feeling, nice to talk to someone who understands and gets the experiences, but just really upsetting that both of us and so many other people have had such difficult experiences when we deserved so much better.

Helen

Yeah, um, I don't know about you but I heard about all these experiences and, but I don't think it wasn't until it started happening to me that I realised, it happened to me and I became aware of, it's just the fact that so many people have such similar stories.

And there are certain words that you mention to anyone involved in services, you know like insight and capacity, and they'll immediately know the connotations.

On the one hand, it's almost reassuring, but on the other hand, it's very sad. And you think, it kind of points to the scale of the problem.

Hattie

Yeah massively. Like it's the sort of connection that you need to find when you're going through a difficult time, but then you don't want anyone else to be going through the same things.

But yeah it has been good to just talk about things and get it out really. It's kind of cathartic, I guess. And to have a space to talk where someone's not gonna come and be defensive or say, well, you know, people are just doing their best, you need to be grateful and you need to understand that the services are pressured.

I understand all those things and I understand that there's been good experiences in this as well but I still wanna fucking moan about it, you know?

Helen

Yeah, totally, I get it. Sometimes I get this kind of, "Oh, you should be grateful". Or sort of, "I'm doing my best" or we've offered you so much". And I know that a lot of the issues are systemic, but people forget that it's individuals who work in that system.

I think there seems to be this idea that bad attitudes come about because it's compassion fatigue, it's burnout etc. And whilst those are totally real issues, valid issues, and I have no doubt that they affect the way staff behave

towards patients, I feel very uncomfortable with the way that's used to almost excuse the behaviour.

It might sound cynical but some of it is genuinely malicious, like Serenity Integrated Mentoring. You just look at that and you think that's deliberately cruel, and policies where they would deliberately instruct staff not to intervene, which is just kind of concerted effort. You know you can't claim that it was, "Oh I'm just burned out". You can't claim that I think.

Hattie

And even if that is the case, it's not like the patient's fault. You know, your excuse doesn't make the experience any easier to have dealt with it. Doesn't mean that it doesn't hurt. Like you can explain it away, but it still hurt. And that's still the experiences that we've had.

So when people try and use that as the excuse to shut down the conversation it's hard because, maybe there are a load of reasons but doesn't mean it's OK.

Helen

Exactly. And this is kind of where, when I said that I got called care seeking, and I said, quite frankly I find it really upsetting. Some people think that it's a nicer term than attention seeking. And I say, no. You're just changing the words, but you're not changing the connotations.

Hattie

Yeah exactly. I think that's a bit patronising because it's really obvious what is meant by the word, so just changing it to sound like a really clunky awkward phrase doesn't change, if you're using it in a particularly loaded meaning. It doesn't matter what you call it, it's about the meaning that you're trying to convey. So it still hurts.

Helen

Exactly. And it's like, I know what they're doing. I know what they're up to. And I kind of I got an apology from the clinician involved, and it was all, "I'm sorry for any upset I may have caused". And it was like, *may* have caused!

Hattie

Ah that's not an apology! That's not taking ownership.

Helen

Exactly! And I was very clear about the fact that I was upset. And then it was like, "It's a phrase that we use to describe..." and this was interesting "...we use it to describe a particular pattern of healthcare utilisation". And it was like, "It wasn't meant to be invalidating".

And I was like, well, first of all, it doesn't matter what your intention was, because it was invalidating regardless. I think there's this culture of, "Oh, that's what we always use. That's what we always say."

They're resistant. They don't reflect. There's no insight and no reflection on why these terms are so harmful. That euphemism, "We use it to describe a certain pattern of healthcare utilisation", yeah you're basically saying you use it to describe people who, in their opinion, probably ask for help excessively.

I decided not to push the matter, because I was like, you know what, I'm not going to get anywhere, they're going to get too defensive, it's going to be like talking to a brick wall again.

I just thought, to preserve my sanity, I'm going to back out of this and just kind of accept. Even though it didn't really give me full closure. I think that's the difficulty.

Hattie

Yeah it's hard when you have to do that. You know what you need you're not going to be able to get. You needed an adequate apology, which includes taking accountability and expressing what is going to be done to prevent that happening again, and to learn from the situation. That's what a real apology is.

And it's difficult in a situation where you know what you need you're not going to get, and you don't have the emotional resources to kind of keep fighting for it. So you just have to sacrifice what you need and call it quits at some point.

Helen

I just think it's ironic that you get driven to that point. I think when I first entered the system I was a lot more hopeful. I genuinely believed that people would have my best interests at heart. And now I'm so much more disillusioned.

Half the time I'm like, what am I even doing here? Trying to correct the injustices. It really wears you down emotionally.

But again, like I say, you feel like you can't walk away. It's just this very very [sighs], I don't know how to describe it, just really strange relationship that you have with them.

Hattie

Yeah, I feel like we both have loads more that we could say [laughs]. I've run out of my energy for today.

Helen

Yeah that's fine, I'm the same. You know when you sort of feel ideas in your head but you don't quite find the words?

Hattie

Yeah, yeah, I'm like, there's this but I just don't know how you, I don't have the words. [laughs]

Helen

Yeah, that's what I feel like, there's so many different strands. And that's totally fine because, even right now I'm struggling to get the words out. There's almost so much I want to say that I don't quite know where to start...

Hattie

Yeah!

Helen

...or where to finish.

