

Chapter 1: Endless Battles

Hattie

I really wish that you could see where I am right now, because it's really funny.

So I moved house a couple of days ago, but I've had to come back to my old house because I don't have Wi Fi yet. And because everywhere is so empty and echoey I've had to build myself a tiny recording studio in a cupboard.

So I'm on the floor in a cupboard, it's a big cupboard in fairness, and then I've got a stack of board games that I found on a wall outside someone's house, and a bedside cupboard drawer as my mic stand. So it's a bit weird. Not the fanciest [laughs] but we're here.

So I'm Hattie, I'm 23, my pronouns are they/them. I really like sewing. I really like sharks and fish. I've got a pet dog called Martha, who I love very much. [pauses] It's hard trying to think about the things about myself and put it into a small amount of space, but there's some things that feel important right now.

Helen

I find it hard too [laughs]. When I get put on the spot, I don't know what to say.

But I'll introduce myself briefly. I'm Helen, I'm 25, and I'm currently here in my room in Cambridge, although I am from Scotland. I have my anglerfish Humphrey with me...

Hattie

He's so good!

Helen

...for moral support - I like soft toys. And I like reading. And I love learning languages. I've just finished a postgraduate degree in comparative literature.

I'm not really sure what to say about my life in general at the moment. It's a bit strange making the transition away from education for the first time in 20 years. And a lot of my time at the moment is spent fighting against mental health services, shall we say?

Do you want to elaborate Hattie on your experiences, your journey through the system first?

Hattie

Yeah, sure. So I have a number of different mental health diagnosis, diagnoses, sisis? I dunno, diagnoses [laughs].

So I think I was first diagnosed with anxiety when I was about 14, but looking back I can recognise that even from the age of about four or something, I can recognise that then I had symptoms of anxiety and OCD. I suppose, at the time, I never had the language to understand that, so I just always thought that I felt sick all the time. And I was actually just really anxious.

I've had a difficult time with my mental health over the past few years. It was especially bad during my late teens. So between when I was 16 to 21 was the worst period. I spent quite a lot of time in and out of hospitals. I was in hospital for quite a while with an eating disorder. And I also was in a specialist personality disorder unit for quite some months as well, at some point.

So I bounced around between inpatient services and community services for a long time, always feeling kind of lost between those things and between the transition and the constant change of that.

I'm currently not under any NHS mental health services. I've made the decision to have private therapy. But generally my mental health now is vastly better than it ever has been. But still, you know, a bit of a battle. A big battle, really.

Helen

I mean I sort of, I can't really pinpoint a time when I went from being mentally well to mentally unwell. I don't think it really works like that but my difficulties mainly started when I left school and went to university, when I was 18. And so in my first year, at the end of my second year, I developed an eating disorder. And when I was 19, I was diagnosed with anorexia.

And since then, I've had a lot of contact with services. I've had contact with them in quite a number of places just because I did my undergrad in one place, and I was briefly in services in my hometown, and then I've been in Cambridge for the last two years doing postgraduate studies.

I've bounced around a lot geographically, but also my presentation, I guess, has sort of evolved. I've gone through periods of doing better with my eating.

And then, about two years ago when I came to Cambridge, I started to relapse quite rapidly. And it's definitely been my worst relapse yet. I'm still very much stuck in it.

And over the last two years I've been quite heavily involved in services, mostly as an outpatient, but also with the crisis services, in general medical wards, in Accident and Emergency.

So I've had a lot of contact with services, which doesn't necessarily equate to having a lot of treatment.

And then just a few months ago I was actually diagnosed with autism, which in itself has been pretty monumental because discovering you're autistic after 25 years of not knowing you're autistic changes the whole way that you look back on your life. So now I realise how much of my mental health difficulties have actually arisen as a result of being autistic and being misunderstood.

For years professionals would label me with personality disorder, and I never really felt it was right. I said, "No, it doesn't make sense". So being diagnosed with autism is extremely liberating. But there's also a lot of anger in that for me.

I look back and I'm like, how did no one pick up on it? How on earth did no one notice?

I think over the last two years I've had a lot of experiences with services. My relationship with them is quite strained, shall we say?

And I can imagine it might probably be the same for you Hattie.

Hattie

Yeah, I mean I've made the decision to discharge myself from services, because I'd had a lot of negative experiences and lost trust in it really.

And there was just an endless sense of, you know, an endless feeling that I was wasting their time. That the things I needed were so far beyond what they had the resources to provide.

But it just felt like a kind of endless battle to try and get the support that I needed.

Helen

I really relate to what you say about it being like an endless battle, because honestly that's what it feels like. It just feels like constant fighting the system. And you're always fighting a losing battle.

On one hand I'm like, why do I keep doing this? Because I know that what they're giving me is just so far from what I need. But then I feel like I need to

keep putting myself through it because I tell myself that if I just keep going maybe they'll finally start to treat me properly.

It's really bizarre that you hang on in the hope that things will get better.

Hattie

I think part of that is that it feels like the only option, because the services that are available are often the only option. If you don't have the financial resources to access private alternatives the NHS is the only option that's available.

So it's being stuck between a rock and a hard place of either you've got no support at all and you're on your own, or you've got the *presence* but not necessarily support that meets the needs. And so it's deciding between that.

There's been times where I've not had a choice to not be involved in services, where I've either been sectioned or given the threat of, "If you do discharge yourself from services, then we will section you".

So it's not always felt like there has been the option to not be engaged in their services.

Helen

Yeah I agree. And I think the way that they frame it, mental health services are very keen on describing us as service users and not patients, which is kind of funny because as you said, you don't often feel that you have much choice.

Like you feel, I don't know about you, but I certainly feel like I've got to a point where I just feel totally backed into a corner where I have to do what they want me to do, because if I try to express any disagreement I just get pathologised and told, "You don't know what's best for you", "We know best".

And it gets to the point that I'm just so exhausted trying to fight them that I'm like, "OK, you win". So I'm sort of complying, but I'm not actually doing it because I want to, I'm doing it because if I don't do this, then, you know, what's the option?

Like for example, earlier this year I was put on something called a SEED pathway - Severe and Enduring Eating Disorder pathway, which wasn't how it was described to me, which I only recently found out. And basically I was told, "We're not forcing you", you know, "This is your choice", but, "This is the only option".

And I told them I didn't want to go on the pathway. I said, "Please don't put me on it. It's not going to help." And it hasn't helped. It's been completely, so incredibly unhelpful.

But I just thought, well, they've basically forced me into choosing this pathway. So I chose it because I was like, well, otherwise they're just gonna discharge me or they're going to say that I'm not engaging.

So I feel coerced into doing things that are actively harmful. But I feel that I have to do it, because I think otherwise, like, I'll just get no support.

Hattie

I'm really sorry that you had that experience. It sounds like such a frightening situation to be in, the sense of feeling so entirely trapped and out of control in the sense of having so few options. Because they're saying, "You don't have to engage in this" but you do have to, which is really hard.

Helen

I don't think I've been treated fairly. And I don't think I've been given the help that I need.

There's a point at which neglect almost becomes coercive, like you're forced into not having choices and you're forced into them just saying, "This is the only option"; "This is all we can do".

Because they keep saying to me, "Oh, there's nothing more we can do"; "We've given you everything". They haven't. That's a lie.

And then you feel like you've got to be all *grateful*, and sort of bow down before them, even though it feels like you're just sort of performing.

Hattie

The use of the word performing really resonates with me, because so often when you've been in mental health services for a long time you learn how to perform in a certain way in order to get your needs met, or partly met in a lukewarm way.

It would be unfair to say that every experience and every individual has been a negative experience, but despite some positive moments the overwhelming experience has been really challenging and a kind of an endless battle to try and advocate for myself, whilst too unwell to do so.

Helen

That's the issue as well, trying to advocate for yourself.

I know when I first entered services, there's no way that I would be as assertive as I am now. I think people don't appreciate just how much energy it takes to advocate for yourself, and it's just exhausting - mentally, physically.

I know I feel like I've had to contort myself into saying what they want me to say and doing what they want me to do. Because you learn that the system rewards you if you play the game. And I say to them, "Look you've given me no option but to play your games".

For example, the clinician involved in my care right now has got this really annoying habit of saying to me, "What do you need?" I tell her what I need and she's like, "Oh, that's not what you need. We don't have the resources." And then like clockwork next appointment, "So what do you need Helen, you've not told us." And I'm like, Jesus Christ! [laughs]

Hattie

That is so annoying!

Helen

I have told you! It's so annoying! And it's like, "I've told you but you just say no all the time, so why should I actually bother?"

People sometimes wonder, they might think that I'm being defeatist, and I'm like, "But there's only so many times that you can hear "no"".

They belittle you and they patronise you and they're paternalistic, you know, *we know what's best*. No, actually, you don't know what's best for me.

Then you come to the point where you just, not that you give up, that's not the right word, but it becomes very very difficult to get them to listen to you. And kind of ironically the more you protest, the more you try to challenge them, the more they try to pathologise you. It's this really weird dynamic.

I don't know if you ever had experiences like that as well, if you ever tried to challenge something and they would use it against you?

Hattie

Yeah, I mean, certainly, and I think what you were saying about when people have asked, "Oh, what do you need?" And then you say, and they're like, "No, that's not what you need, we know better."

I find it so frustrating, because you can do 1000 medical degrees and read every book in the world, but you're still not gonna know me better than I do. And it's so frustrating when you know yourself and you know what you need and that's not respected or listened to.

So, this was with Occupational Health. I'd had a bit of time off work because of my mental health and I had to speak to the occupational health doctor before I could be signed back to work. And because of the pandemic, it was just a telephone appointment. And I was saying, this is the situation, this is what happened, this is where I am now, I feel ready to come back to work because of X, Y, and Z.

And he was very much not interested in listening to what I had to say. He just cut me off and then said that he was going to write to my GP to ask them to write a letter about my mental health. And it was the most frustrating experience because I was like, I wish you could just listen to me. I have never met my GP. My GP doesn't know me. All they have is some very brief medical notes. Why is that given more validity than what I have to say?

Our word is always valued less than that of a medical professional because they're the ones who have the power and they have the medical knowledge. I'm not saying there's no value in that, but that's worthless without listening to the individual and their understanding of their experiences.

Helen

I completely agree. And it's something I've noticed since being diagnosed with autism. Their treatment of me has been even worse because they just, they haven't taken it into account at all.

I find it quite annoying, because they'll try to explain autism to me. And I'm like, look, I was only just diagnosed but it doesn't mean that I was not autistic one day and then autistic the next day. You're born autistic, you die autistic. It's when they try to explain it to me, and obviously they get it all wrong.

One of them said to me, "Well autistic people can't understand other people's motivations and intentions". Saying that to imply that that was why I didn't understand why the team was treating me unfairly. Although she said, "Oh, that's just your perspective that we're treating you unfairly". Which I said, "Well, that's just your perspective that you're treating me fairly." [laughs]

Hattie

Who gets to say whose perspective is more valid than others, right?

Helen

Yeah exactly! It was just the way she was saying it as if, that's your perspective therefore it's inferior, therefore you're wrong. As if, because I am autistic, that I'm inherently unreliable.

And it was like, “Look, the reason I don't understand you is because you don't explain, you know, I ask you for explanations and you don't give them to me.” It's a two-way street.

And they just kind of fail to see their role in that. It's all about me not understanding them and not about them misunderstanding me.

Hattie

Yeah, do you ever feel that once you've been given a diagnosis that that changes the lens that somebody views you in, and suddenly everything is pathologised, and kind of seen through this sort of like, “You're mental, so every single aspect of you is therefore mental”?

Like I had a kind of assessment with mental health services a while ago, and they were, I know it's standard questions but they were asking about the amount of alcohol I drink. And I said, “I have a little bit”. And he was very fixed on this question and was asking a lot of questions.

I think the fact that he had seen my medical notes and seen the diagnosis I had meant that he automatically assumed that me having a beer at the weekend was suddenly part of my illness rather than just being a 23-year-old person, you know?

Helen

Yeah, I know what you mean and I don't know if you found as well with your eating disorder, but for me, it'll be like, “That's the anorexia talking”. And I'm like, “No, it's me talking”. And everything they attribute to that.

Especially when being autistic. There was one time I remember being on a medical ward, and they just put me on this standard re-feeding meal plan. I suppose it's pretty generic. And I remember they gave me a bowl of cereal with milk. And I don't really like milk in my cereal. So I said, “Oh, can I have something else? Like maybe some toast or something?” So I did ask for a replacement, like I wasn't just refusing. But I think they just thought I was being so deliberately difficult, and it was just, “Oh that's just the illness”. And actually it's nothing to do with the illness. I've just never liked cereal with milk.

Hattie

Yeah they see it as being because of an illness rather than just a personal taste that everyone has.

When I was inpatient for an eating disorder there was a bizarre rule that you couldn't have the same type of cereal for breakfast every day. And they made this rota, like this actual chart of which days you could have which cereals, so you didn't have the same one.

And the only cereal that I like is Shreddies. Shreddies is the best cereal. And they made this into a huge thing. They were like, “Oh, this is your eating disorder saying you can only eat this type of cereal.” And I was like, “Well actually having food preferences is a very, very standard thing. Why is this suddenly weird because of the context of my illness? I actually just like Shreddies. They taste nice. I like it when I mash them up. Just let me eat them in the way I want to eat them.”

Why has everything got to be to do with the illness?

Helen

I know! It’s like they try so hard to find some sort of disorder reason. You just like Shreddies!

My parents they have the same, for breakfast they always have muesli. And no one’s going around saying they’re disordered! Some people are more rigid in their food choices than I am, and they don’t have eating disorders!

Hattie

Yeah I mean I don't know anyone who has to have Cheerios on a Wednesday because they hate them but they had Shreddies yesterday so they can't have the same cereal two days in a row. And maybe if that's a thing that sounds [laughs] a little unhealthy as well!

Helen

Yeah it’s when you take a lot of these rules outside of their context you realise how abnormal the rules are.

It’s no wonder a lot of people go into these places, they come out, you know they go in and out. That’s my impression, that a lot of these rules are rules that outside those four walls, well who actually adheres to that?

And you hear people talking about how they go into these places and come out and they almost pick up new habits. You sometimes wonder, do these places harm more than they actually help?

