

This transcript is automated, and so may have some mistakes. We're working to hand correct these, but are keen that some was available in the interim so have uploaded these temporarily.

[00:00:00] **Imogen:** My aspiration in life is to be a massive cripple.

[00:00:16] **Suriya:** Welcome to Sickbabe the podcast from my bed to yours here, we'll be chatting about all the things that it means to be invisibly sick or disabled, chronically ill, whatever words you choose. We'll be talking about everything from sex to Mary on Facebook, who thinks she knows more about your condition than you do.

[00:00:34] Um, and we hope that it can be a GC bedside chat for those days that you don't have loads of energy and maybe just something to keep you company on the days that you feel. All right. And if you're not sick or disabled, don't worry. You can still listen. Turns out capitalism and ableism is screwing us all over.

[00:00:52] All right, let's go. Hey, sick babes. I can't wait to share this conversation with you today. I had the absolute pleasure of chatting to image and Fox. Um, imaging uses they them and she pronouns and they are a queer, disabled femme, seven radical body politics they started. Um, and a lot of their activism is formed in anti diet culture and they just want to spread lots of non-judgemental compassion in the activism and artistry that they do.

[00:01:21] I have been following imaging for a long time on Instagram. Please do check out their, um, Instagram page, the feeding of the Fox. And we'll link that down below, um, where they talk a lot about their experience of living with an invisible and often sometimes visible chronic illness, um, and disability. They kind of advocate a lot for the disability community.

[00:01:44] Um, and I really appreciate their voice and humor, which you'll see in this conversation. So I really hope you enjoy this episode. Trigger warning for this episode, we talk a lot about being in hospital and the experiences of that. We will link the timestamps in the description below. I

[00:02:01] **Imogen:** started just sharing my life ready, um, slightly awkwardly.

[00:02:06] It definitely started as a diet account. So that's like how I started gaining it like a small following. My Instagram was mostly around weight loss. And then when I discovered, um, body acceptance, body neutrality, That's for me when I'm like, all my politics kind of dropped into place. So what I, like I

was raised as a disabled person, like say ways, my best mate, who I met when I was 16, she was 10 years older than me.

[00:02:35] She was properly radical. She was already on the streets, like doing demos, part of the direct action network. She lived up in Manchester, she was queer and she like gave me this radical education. So. I totally was in it. Disability rights, there's ability, politics. I was completely in it. I was on the streets to doing all the demos.

[00:02:55] Like it was great fun. Um, but I don't think I ever really realized that body politics certainly radical body politics stretched way, way beyond just like discipline, like just the kind of niche intersections. So like, I, I didn't do any anti-racism work. I didn't do any anti fatphobia work. Like all of that stuff.

[00:03:14] Like, it just didn't really click for me until I realized that I actually made myself really, really unwell by dieting, like having an eating disorder essentially. Um, And then, so all the politics around kind of fatness fatphobia body acceptance, body neutrality kind of clicked in with my disability rights work.

[00:03:34] And I, all of a sudden, like there was this like, ah, light bulb moment of, oh crap, all bodies. I okay. Right. I get it now. You know, so then I guess like my work kind of stretched out from there really like started to cover a lot more bases. I'm like, I'm still learning. Like I still get it wrong all the time.

[00:03:52] And I guess that's sort of, um, part of political work, isn't it? It is like putting your foot in it and being like, Ooh, oops, didn't mean to do that. And that, you know, educating yourself and going out and trying to do it better. But yeah, like just living with an impairment is really hard work and being a queer person within that too, like just makes it a little bit harder again and being a person of color, like for you, makes it harder again, like there's just, there's so much going on for so many people just needs, needs more conversation.

[00:04:22] Doesn't it. But I did a photography degree in my early twenties. Like art was always part of my life. And, um, I find it really difficult now to acknowledge myself as an artist. I don't feel like I produce enough to be an artist. I don't feel like I write enough to be a, uh, an activist, but I guess I took a couple of boxes somewhere.

[00:04:41] Do you know what I mean? Like,

[00:04:42] **Suriya:** definitely. It's, it's re it's really isn't it. It's like, how do we choose to define as an artist and a writer? And from my outside perspective, I would definitely say that it is different, the photo photographs in your photography scale. And I obvious, um, now you said that you'd done a degree, which is really powerful on your page and also the writing that you do around it.

[00:05:06] I think it's, I think that in itself is really without trying to sound like super fun. It's re it's really, for me, it's kind of like, you see the image and then you, and then what you're saying might be just like. Not sharing this to, I don't want to talk about what's actually going on with my body. Like that's hiring for me because I think at the beginning of when we're having a diagnosis, so I was, I lived with kind of, um, symptoms from childhood, but it was only dark when I was 17.

[00:05:37] Um, and so really learning how to navigate, how to talk about my disability without going on the kind of long medical list of like it's a hundred percent. And also like, no one really understands it anyway, because my condition is really rare. So it's like, they're like, what's that? And then I have to use another condition.

[00:05:53] So like, just really is so actually being able to be empowered, to be like, yeah, I'm disabled. And this is, these are my access needs. And that's it like you don't

[00:06:02] **Imogen:** yeah, this is what you're allowed to have access to. Yeah. It, honestly, it still amazes me the number of people who drop into my dams being like, what, what is wrong with you?

[00:06:11] Exactly. And I'm

[00:06:14] **Suriya:** probably just not that question really delete, you know? Yeah. It's the entitlement to our bodies. I guess there's like femmes as like Sable people, queer people who are queerness has become this commodity as well as like the industry I can imagine is a massive thing for you.

[00:06:36] **Imogen:** Yeah. It's been really difficult.

[00:06:38] And I think like, um, I don't know how to talk about this. It's really tricky. So I left my partner of 10 years at the end of last year. Um, and the prospect of like sharing my body with somebody completely new again. Now maybe it's just like blowing my mind a little bit. I like, I don't know about how,

like how often you're in hospital and obviously lots of disabled people aren't in hospital, but they still experience a similar kind of thing I think is that there's, um, you enter a room and suddenly your body isn't your own anymore.

[00:07:14] Like other people are just allowed to touch you and ask you questions and they expect, um, unimaginable amounts of like painfully private and personal information from you. And the prospect of like going into a space where I want to share my body, but I just, I don't know how you're meant to navigate those so challenging, but then like, I'm also super conditioned to be like, oh, I'm sorry about this.

[00:07:42] And these are my symptoms. And like, oh, those spaces are just so tricky to navigate. And even now, like, so you say you were diagnosed at 17. Like my symptoms started in childhood and, and got significantly worse in my early teens, but I wasn't diagnosed until. Like it was 2011. I don't even want to think about how old I was then, but I was like properly late twenties.

[00:08:05] So I'd gone almost a decade of really severe impairment, like in and out of intensive care, really, really poorly for a long time and no diagnosis. So I just had nothing to kind of cling onto, but it also meant that I was constantly like new doctors, new people will tell me about their scans. Tell me about that.

[00:08:24] Like blood tests, being poked and prodded and people kind of just like trying things and that not working and trying something else and that not working, like the amount of trauma that I experienced in those 10 years alone is like enough to give anybody complex PTSD. Do you know? Like it was just such a wild time, but that, like, I don't know how I meant to make peace with the fact that my body is only sometimes mine Laris.

[00:08:51] **Suriya:** Well, yeah, no, I really hear that. I, and I think one of the things, especially over lockdown that I've realized is how much trauma I have from the hospital and how much of my life is spent, trying to, I mean, when you, when you're disabled and when you're chronically ill, you realize that, you know, Our body is so much not in our control, then people, you know, there's this kind of, um, you know, the mainstream is like, eat this and you'll be fine and you'll never get a disease and you'll never be sick.

[00:09:23] And it's kind of like, yeah, like all disabled people just laugh at that. Cause it's like, I don't everything. And I'm still here. So it's, it's not, it's not about that. But how much of my life is still kind of falsely related to going to try and stay out of hospital. We got to try and like, not do this stains so much.

[00:09:41] Like last year before the pandemic started, it was, uh, it was ironic. I don't know whether it was some like weird we were thing, but I was like trying to research masks, um, to get some before we knew it was coronavirus. Cause every flu season I'm really, like, I sometimes ended up in hospital and flu season.

[00:09:58] Cause I have like symptoms of like a stroke kind of thing or.

[00:10:03] I just read about what I got and then I ordered some and they didn't come. And I was like, oh, weird. Then actually it turned out it's because it was massive, like pandemic, literally. So

[00:10:20] I think I really have started to realize, oh yeah, like you go into hospital and you have to kind of dissociate for half of the time. Do you find that that

[00:10:30] **Imogen:** it's really changed your experience within your body though? Because I felt like I'm in this really weird situation where I am both wildly, intimately connected to my body and I know all the fucking things, wait, am I allowed?

[00:10:47] Of course. Okay, great. So late to the party on that one, sorry. I should have asked that first really shouldn't I, but also like completely unaware and totally disassociated from it. So for example, um, I remember this one time I went into and like, I don't know about you, but I know my clinical team really well.

[00:11:06] And, um, he'd come down. One of my doctors had come down to meet me at Ana and I was like, oh babe, just, you know, hit me up with the usual drugs. I'll be out. You know what I mean? And he was like, imaging, your liver has failed. So we're definitely admitting you. And I was like, oh shit, the bed. I had no idea that was so poorly.

[00:11:22] And then there's other times I go, no, there's definitely something wrong guys. Like the shit's hit the fan. I am not well. And they're like, yeah, your bloods are absolutely fine, but I just. I feel so like totally connected in some ways that I'm not all can't do that. Or I could meet this today or like, I know my limits.

[00:11:41] And then on the other hand, like, I'm so used to just being like, oh, that pains nothing. Like, let's just like, I went in once I found my team and I was

like, I've just got this peer chest pain. Like, I don't think it's a big age. Just don't worry about it. And they were like, let's just do some bloods couch.

[00:11:56] Be absolutely fine. I'm sure my potassium was like warden. They were like call an ambulance and it's like, literally get to the hospital right now. Yeah. It's, I just don't really know where that kind of line is meant to fall between. Like, when are you just the annoying patient who rings constantly because you don't feel quite right.

[00:12:14] And they solve nothing really wrong. And when are you that like really annoying person who leaves it until the very last minute. And then it's like really profoundly unwell,

[00:12:23] **Suriya:** but it's just, oh, it's so complicated. I really relate to that. That's like, I feel like, you know, I feel like it's eggs sometimes talking to other disabled folks is like a game where you like, unlock a memory where you're like, oh my God.

[00:12:37] Yeah. I remember that time. Or, or like you unlock it an experience where it's like, I didn't really know. I know that that's happening for me, but I don't really talk about it. So yeah, that's really really thing. Cause I've been having like new pains and it's like, some of my, of my friends call it like Mughal sick where you're like, you know, normal people, six like, oh, this is just a Mughal sick thing.

[00:12:58] Like I, um, I can't be bothered to like go and do this investigation, but then I have a moment of hyper-awareness where I'm like, what if it's like actually a really serious thing. And then I'm like, didn't get it sorted. So, yeah, I I'm totally. Um, and sometimes it's just like, um, really it's just that the sick admin is so exhausting.

[00:13:21] Cause you're like you might come from right from the hospital for one thing, and then you like. Oh, great. Okay. I guess I got like email about that last time I

[00:13:31] **Imogen:** came up hospital, I was like, I think I've got blood clot guys. I'm just going to, like, I lasted less

[00:13:35] **Suriya:** than 24 hours. And I was

[00:13:37] **Imogen:** back in my blood clot.

[00:13:38] I was like, fuck sake. Like it's just this domino effect constantly. And then of course, while you're in hospital, you can't do all the other things that you would usually be doing for sick admin. Usually I miss half my drugs. Like it usually creates a shitstorm of other impairment related bullshit that you couldn't manage while you were in hospital.

[00:13:57] There's like appointments have piled up at home that you've missed because you've been in hospital for so long. Yeah. I honestly how like non-disabled people like deal with their car insurance and have a job I'm like. Honestly, my mind is blown. Like I can't decide whether they must just have so much time on their hands, that they can just do all the things or whether like life just comes to a complete standstill, because I'm just like, honestly, I could show you about 45 pieces of paper, right.

[00:14:29] Literally right here of like lists of shit that I need to do. And I'm like, I am quite tired today. So Matt just needs,

[00:14:38] **Suriya:** do I take care of the body that I'm hearing or do I like take care of my body in a couple of weeks when I know I don't deal with this load, it's just what I it's just so

[00:14:50] **Imogen:** bored. I'm so done.

[00:14:51] I'm so bored. I also, like, I hate asking other people I don't know about you. I'm just like, I'm sorry. I feel so desperately conditioned now to be like, must do this by myself. Mustn't ask for help. Must be like the strong, independent, disabled person. Mustn't like. You know, or use my friends, like take the piss out of them or take advantage of their kindness.

[00:15:15] I don't want to be the person that everybody has to rescue. Like I need to be the person who brings to the party and like, make sure that all our relationships are like equal and balanced. And, uh, but it's so hard. Like, I don't know at what point I meant to just code, you know what, actually I left home would be cracking.

[00:15:32] Thanks so much. Yes. Please pick me up. Or if you're at the supermarket, could you just do my shopping? I've just got a small list. That'd be great banks, but like at what point do you like stop dragging yourself? Through all sorts of torture in order to be like, oh, I'm totally managing this, like nailing life.

[00:15:52] Come

[00:15:52] **Suriya:** on guys. Yeah. Something like the good disabled to be like,

[00:15:58] because, because it is the perception of disabled folks in mainstream society, is it it's like, you're either the poor infantilized, like really weak foreign, who everybody has skew or you're like, you really, you like inspire me, man. Like, you know, you're ever coming here and you understand. And then even when you try and like, not be that person, you're still like, oh, somehow I can only get rec you know, not recognition, but like a hundred

[00:16:27] **Imogen:** percent, one or the other.

[00:16:28] Right? Like, it feels almost impossible to find like a kind of line in the middle where, where it's comfortable, where you feel like you're asking your friends for the things that you need having your needs met or whatever. But, but that it is. Like wildly inappropriate petty me I'm desperately in need of support, but also that you're not like sailing high.

[00:16:50] Like you're being honest about what's happening for you. But I don't, I don't, it doesn't feel like that there, there is that mid point, particularly. I feel like certainly for me, I feel like I flip between one and the other one, I'm like completely half dead. Like someone's going to have to come and rescue me now.

[00:17:08] Cause like I'm just, I'm done. Or like, absolutely not. No I'm stoic. Like I will tell the better end over my dead body that I just, I don't know how to find that kind of middle ground and society doesn't make it any easier because if you're not one of those two, you've got to be a fucking Paralympian. You get to me.

[00:17:27] **Suriya:** I definitely went through that phase after I was to be like, when I was younger and I was like, how can I still be parent? Why am I trying to be a Paralympian? Like it's not, and I'm emailing all these people biting, like, yeah, this is the way. And like emailing the, um, the coach has to be like, yeah, the doctor says like, if I do show you is X size size, I will pass out.

[00:17:51] Or I might like have a seizure, but

[00:17:57] being like, you know, the doctors, but honestly it's taken me ages to accept my new, the new prospect of my body, you know? I mean, and I think, cause I think there's no, you know, we don't have. Any, um, blueprint or trajectory for like successful disabled people do it, you know, when you're younger, you go, you know, when I'm older, I really want to be safe.

[00:18:22] Do you know what I mean? It's like

[00:18:25] **Imogen:** aspiration in life is to be a massive cripple.

[00:18:32] **Suriya:** Now I feel like I'm just fighting to get that to be like, how do I celebrate my disability and be like, you know, it's kind of like funny and awkward in ways. And you know, it allows me to see things differently. Blah-di-blah like cliché things, cliché things are true. That kind of, um, like earlier you referenced body neutrality and I wondered if you could tell folks like what that means, like in general it means for you.

[00:19:03] Cause I feel like that discovering that recently has really helped me shift a lot of things as well. Yeah. So,

[00:19:08] **Imogen:** um, when I like started to recover from my eating disorder, um, or entered like a recovery focus sort of thing, that was really terribly worded, basically what I mean is that you can't just be recovered from an eating disorder.

[00:19:25] Like it takes time. So it's still like a focus and an aim rather than like a, you know, done it type thing. Um, so I found like body positivity, um, and obviously like looking back now made a lot of misses. In terms of that, like it's a really whitewashed movement and there's a lot of, um, there's just a lot of niche politics around it.

[00:19:46] There's probably a bit pointless to try and explain, but basically within body positivity, there was this idea that you could kind of find a, uh, uh, a place in your, in yourself where you felt confident and some kind of love for your body. And actually, I think certainly within the queer disabled community, we kind of cottoned on pretty quickly that just like casually loving oneself, probably wasn't really top of our to-do list because actually loving a body that is fucking useless at times is really hard work and loving a body that like, um, means that you're oppressed in society means that you don't have access to things means that you're denied a shit ton of stuff.

[00:20:25] Like. Lee. That's just a no from me. Thanks very much. But body neutrality is this kind of place where you just feel new, literally neutral about it. It doesn't have to be positive, but it also doesn't have to be negative. And I think there's like, there's a lot of nuance within that, right? Like it's okay to wake up in the morning and just be like, oh God, I'm in pain.

[00:20:47] And that is just so shit. And I, I feel shit about my body right now, but actually to be able to then your next thought B, but you know, it's trying, I am going to be able to do a couple of things today, or I'm not going to be able to do a couple of things today, but at least I'm in bed. And like, just to find a space where you're just, you know, just some kind of acceptance and I mean, in some ways, It almost feels like quitting the fight a little bit.

[00:21:19] Like just that kind of, do you know what, like, I don't want to fight my body. Like I don't, I really hate, I don't know how you feel about this, but the whole, like, um, so interestingly, I was just about to ask you about this. I feel like there's kind of two niche camps, so everybody might consider themselves to be disabled or not.

[00:21:40] That's kind of political, but within that, it's kind of, um, chronic illness and then people with like physical impairment and then they might be two different things. So I feel like I can. Maybe covered both a little bit. Like I have chronic health stuff, but also have a physical impairment. And I, as an umbrella term, I consider myself a disabled person like politically, but I feel like this whole I'm a chronic illness warrior bullshit.

[00:22:09] All right. Just please get in the bin. Oh my God. Like I am guys, I'm tired. I don't want to have to fight anything. Like I'm, I'm busy. Like I'm really busy. All the

[00:22:21] **Suriya:** other things literally would be like, why is this not happened? I asked you five times already.

[00:22:30] **Imogen:** Yeah. Hello. Thank you. Like where is my prescription that I asked for six months ago and still hasn't been delivered, like, yeah, I just, I don't have time to be.

[00:22:41] Fighting against my own body. And also like, I, I don't think that's okay. Like I think what we know about auto immune diseases now and impairment really across the board is that if you live a life where you talk shit about yourself and you are constantly kind of fighting your body and surrounded by shame and oppressed by society around you, like.

[00:23:08] Your body

[00:23:09] **Suriya:** will argue back

[00:23:10] **Imogen:** to that. Like you're going to create a shitstorm inside every cell in your body. So for me, very long-winded body neutrality was a place where I could let myself breathe again and just be like, Okay. Deep breath. Like it doesn't have to be one or the other. We don't have to be okay or not.

[00:23:30] Okay. We can just sit in the middle and nobody's fighting anybody. And today is what it is today. And tomorrow will be what it is tomorrow. And I'm going to have feelings about that and that's totally okay. Or my feelings of our lead, but I don't have to be involved with them all of the time and, and be arguing with them constantly.

[00:23:50] And I guess like, so part of eating disorder, recovery, right. Is acknowledging that the things that you think and feel are there, they're real, like they're happening inside of your head, but you don't have to have a fucking conversation with them. Do you know what I mean? Like if you've got some dickhead in your mind giving it that, but it's just, you probably shouldn't be eating that like, well, you probably need to pipe down to, I mean, like we need to, literally, I've got now.

[00:24:16] It just, it doesn't need to be an ongoing conversation, be invested at all, all those thoughts and feelings and it took it like, it definitely takes practice. Mindfulness annoyingly is useful for that kind of thing, but yeah, just like just moving away from that whole, like, you have to fight, you have to feel positive or you have to love yourself.

[00:24:35] Like I'm under enough pressure to do a shit ton of stuff. Like I don't have to feel that thing

[00:24:41] **Suriya:** basically. I totally I'm with you. I'm with you. I hate the fight talk. I hate the warrior talk like, um, yeah, sometimes as a joke, my partner, um, calls me zip warrior because that's like the term for one of my conditions.

[00:24:56] Cause I'm going to zip up like a scar at the back of my head. So, um, but like it's a joke. This is not like this. There's nothing where, you know, I think obviously some people gives them great, you know, it gets them through blah, blah, blah. Yeah, for me, I'm like, when I'm in hospital, I'm not fighting anything.

[00:25:19] I'm just laying there being pumped in what I'm being pumped with. And it's like, maybe I'll survive and be stronger out of it. Maybe I won't like, there's no way to know. And often what influences that is like my age, or like

what's going on in my body, the stress levels, the support that I've got around me.

[00:25:37] Like, you know, so that even the whole talk around in the COVID pandemic has been really triggering in the sense of like, well, you know, he survived, but he fought it. He won the battle and it's like, What are we talking about? Like, so everybody who didn't, who died lost, like, you know, some people live like some correlations between that, but we weren't know everything.

[00:25:58] And I think part of like, yeah, like you said, not having conversations with everything all the time. I think it's something like, it's almost like a skill that I think some disabled folks, um, have to kind of, you have to kind of pin down because it's not everyday that you couldn't be doing Googling, Googling and reset, you know, you can't like, you just kind of make your site.

[00:26:22] You said, make yourself stressed, make potentially worse. The quick question you said about like chronically ill and physically impaired. And I think I straddle both of them as well at different times of the month know, and, you know, depending on how I feel, I want to talk about it. I think it's really important for me to.

[00:26:43] Adapt disabled as like a political term for myself. Um, but how, and then how I describe my, um, body, I think it changes depending on where I'm at, but like you said, it's kind of like sometimes, like I can't bother to even think about it. You know what I mean? It's just laying there and all I can think about is the fact that I'm really tired and it needs to just like, you know, watch Netflix.

[00:27:10] I don't really think about it more than that.

[00:27:13] **Imogen:** Yeah, totally understand. I think, um, the whole survival thing I find really challenging too. So I wrote a post not very long ago, actually. Maybe I was in hospital and I, I think, um, I'd seen in somebody's story. I don't know if you've seen the meme. I mean, there's millions of them obviously, but, um, uh, I've survived all of my worst days or you've survived a hundred percent of your worst days.

[00:27:37] I think that's what it said. I literally just wrote a post being like, dude, do you know for a moment though, what surviving looks like for people like me, like surviving intensive care and comas and sepsis, like, I didn't survive without massive fucking trauma. I didn't survive about PTSD. I didn't survive about the most unimaginable flashbacks and trauma and pain.

[00:28:06] Like just, uh, just saying, oh, you've survived a hundred percent of your worst days is just like, it's it, it shrinks the trauma down into something useless. Yeah. I, I just think like when. When we talk about surviving, it really diminishes the ways in which surviving is damaging and the ongoing, like lasting effects of surviving when you're, you're living a life like we're living.

[00:28:41] I, I get it. So those sorts of, um, motivational quotes, I think there was sort of written for people with mental health conditions and like, I understand where that comes from, but they're platitudes, right. They're meant to just like pick you up in a moment where you're feeling a bit vulnerable or sad and just be like, don't, you know, don't worry.

[00:28:59] It's going to be okay. And in many ways, like it will just be okay, because the reality is we have a fucking choice, which is going to have to get on with it. Like, that's my other least favorite thing. Oh my God. What's that one.

[00:29:11] **Suriya:** Um, oh, what is that mean? And it's like,

[00:29:16] **Imogen:** is it like about coping? Like grouping?

[00:29:19] Yeah. Yeah.

[00:29:20] **Suriya:** Say that again. I was going to say, is it the stronger than you believe.

[00:29:25] **Imogen:** Yes. Yes. I just think it was

[00:29:31] **Suriya:** like most hated memes for like, it needs to be a page.

[00:29:37] **Imogen:** It should be a page or a page. I

[00:29:41] **Suriya:** see those things. Or it's like when you've got the same 24 hours as Beyonce and I'm like, yeah, I'm pretty sure Beyonce doesn't have medical conditions.

[00:29:49] I have. So it's, I'm

[00:29:54] literally drank four hours

[00:29:56] **Imogen:** would look very different literally.

[00:30:00] **Suriya:** Oh my God. Being sick is so expensive. And then I'm not saying it like in a, in a country where we have the NHS and all these things, it's still. So like, you know, cause I, cause my condition, there's not, cause it's, there's not many cause it's underfunded and the research and blah, blah, blah.

[00:30:19] There's nothing I can do other than like go to a surgeon and he's like, well, I can cut you open again. If you want, we can. And I'm like, no. Or do you want this tablet? It's probably going to make you maybe in fertile and sleepy for the majority of the day, but you won't be impacted. And I'm like,

[00:30:39] no. So obviously that means that I go, I have to go. Right. Okay. What vitamins or supplements am I going to get together basis of being able to cope, but they're bloody expensive and they're not, they're not eat like,

[00:30:50] **Imogen:** so there was some research done. Um, like probably, I mean it's probably a good few years old now I cannot think of the charities name.

[00:30:58] That's really bad. Oh, I can't remember. I could find it for you if you wanted to know that I definitely wrote a post about it, but I think they were saying that it costs something like an extra. Oh, this is terrible. I'm not, I'm going to stop talking because this is not the right information. I'm going to find it though.

[00:31:18] Hold on.

[00:31:20] **Suriya:** Yeah, no,

[00:31:21] **Imogen:** there was actual like an actual charity, um, an actual post about how much it costs it to be a disabled person. And it was literally hundreds of pounds a week. Like actually hundreds of,

[00:31:36] **Suriya:** I have to just not really think about it. Cause it should just be doing all that you, you deciding, oh, I'm going to buy these like supplements over like new top or something.

[00:31:45] And you felt like it was actually interesting. Cause I often think about like my teenage years and like train, not to use the language around, lost them, but it did feel like how much different of a teenage year that I had because, because I, you know, Oh, trying to figure out what is my personalities. It's a bit of a strange thing because when I was younger, I had to be, I was quite an outgoing young child.

[00:32:10] And then when I was diagnosed, I became really cautious because I was so scared about, um, like what was going to happen. And I couldn't be in places where like flashing lights or dark or like, you know, I would, things would change really quickly. And so I spent a lot of the time actually at home, didn't go clubbing or anything like that.

[00:32:29] So I kind of. Developed a different, like, it was like, I was a different, that was a different personality, but it's also like, I'm kind of watching myself, knowing that that personality isn't necessarily like me, but what, what is me? Because you know, there was all these social factors that influenced that, you know, young people don't really know, you're still learning how to care for each other.

[00:32:52] So a lot of going not going clubbing was like, what if someone just leaves me on the floor? Like if I fall over or something

[00:32:58] **Imogen:** or you're drunk and doesn't get you the help you need. Yeah.

[00:33:04] **Suriya:** All these things. So it was like, I feel like only now, like now I'm hitting nitty fat is it's like, oh, okay. So I like that.

[00:33:13] Like, things like that, I might, I don't know if I could be. So it's just also those things of, like you said, the distance between you and your body, but then also like you and your personality or. I really related to what you said about the independent, cause I'm like a staunchly quite independent person, like yeah, just do it myself.

[00:33:35] Don't worry, blah, blah, blah. And then having to like, realize that, okay, I've got to go to like ask for help, which is not a bad thing for anyone anyway. So it's just the, it's just a constant, um, it's like a conundrum and I've had to like train some of my friends and, um, my partner to like spot when I'm not okay.

[00:33:56] But I'm not saying like, I'm not saying, cause like, they'll be like, if I, for whatever reason, just watching Netflix for like three days in a row, it might be that we need to, like, you need to ask me, am I like in pain or something? Cause I don't know if I'm, if I should go how to communicate that or whether I know him that I'm knowing that I'm struggling to communicate that sometimes I don't know if I'm in pain because I'm in pain prime.

[00:34:19] And I don't know if it's risen or it's really.

[00:34:23] **Imogen:** This is so nuanced, isn't it? Yeah, I, um, I didn't, I was a full-time wheelchair user for 12 years. I only learned to walk really, really recently, like three years ago. Um, and I love going on long walks. Like I absolutely love it. And I like the whole of my twenties.

[00:34:43] So I started using a wheelchair like 19 and I didn't learn to walk until. Um, like early thirties. Yeah. Like mid thirties, even like, I just, I had, there was so many like physical things that I might have enjoyed doing that. I didn't like, I didn't take any drugs. Like literally, literally no drugs guys. I mean, obviously hospital

[00:35:07] **Suriya:** it's like getting dealt drugs where you got through.

[00:35:09] It's just not,

[00:35:12] **Imogen:** I did catch men in hospital and it was, it was awful because I thought my surgeon was a spider. She had like AIS and every time she moved her arms, it was like she had eight legs. I just kicked her in the face.

[00:35:25] **Suriya:** Talking to me when I did come in as well after I helped put my whole bed was on fire and this person came and I was like, I'm always like, I just look to the text in the morning.

[00:35:34] I was texting my family, all this kind of it. Like, I just feel so great, but I'm also very scared.

[00:35:44] He might tell you silly, it's a

[00:35:45] **Imogen:** no thank-you but now I'm like, should I get some MTMA like that? I mean, that sounds like it might be quite fun, but as a, like almost 40 year old, I'm like, is that allowed? Like, am I allowed to start taking them? Dare me now. And just have no idea

[00:36:01] **Suriya:** I'm with you. I mean, I totally like here dot fingernail.

[00:36:06] And also, and also being like, I remember one of my friends and had a conversation where I was like, I kind of had this weird reaction about MTMA where I was like, what, what if it like kills you? And you just don't know. But I think that fear comes from being Husayn going like, I'm like, I wish you say I'm going to be the one that's going to dry it.

[00:36:25] And everyone else is going to be fine. I'm the one who has a really bad trip. She trying to be at peace with being like, maybe you're not, maybe I should have your buddies from me taking harder drugs, like you said,

[00:36:41] but it is, it's that thing of, and it's also you're ingesting the society's idea of what a disabled person is. Isn't it it's like, you're not like a party goer, disabled people don't pay. Like they don't do drugs. They don't like, they just sit at home and cry. And I don't know when they're claps, when they make a cup of tea or something, I wish more

[00:37:00] **Music:** people come through to make a cup of tea.

[00:37:05] **Suriya:** Who is going to make that app like that, just like cops, every time we do something, I feel actually helped my life

[00:37:11] **Imogen:** motivational. I think it would. I wonder, I'll say whether there's like, um, for me, like obviously having lived like, so I was saying to one of my friends the other day, I feel like I'm the most passing I've ever been in my whole life, because as a full-time wheelchair user, I was also fat as a wheelchair user.

[00:37:30] And I mean, I think I'm probably reasonably queer presenting in most spaces, but I dunno, I'm also femme enough that I, I totally, um, like I pull it off. Do you know what I mean? But like being a fat wheelchair using queer person is so different to being a thin walkie. Kind of queer fam looking person, like how I'm responded to in society now is so completely different to how it was responded to previously.

[00:38:04] And I think. That, I mean it growing, I feel quite fortunate in some ways I've experienced both because it gives me, um, you know, I can look back and acknowledge the differences in privilege and that kind of stuff. And it helps certainly in terms of writing to be able to kind of cover many bases, but now I'm like, it's, it's wild, how differently I'm responded to in so many spaces.

[00:38:28] And also how many more freedoms I'm granted as a result of just being thin. Like literally just being thin if I like, cause obviously in the, in the middle of that. So I was like a fat wheelchair user, but then I was a smaller fat wheelchair user. And then eventually I was, um, a thin manual wheelchair user and then eventually kind of crutches and then walking, but all the ways in which I was responded to differently, it like honestly blows my mind.

[00:39:01] I remember being in intensive care once and, um, Uh, I had actually had to be resuscitated on the ward. So they'd called the crash team and then I had gone into intensive care and they'd intubated me and they, they try and take the tubes out as quickly as possible. Right. So I was extubated the next day and I was trying to breathe myself and I was on a hundred percent oxygen, honestly, probably one of the worst experiences of my life.

[00:39:26] And I remember the nurse saying to me, you're doing this to yourself and I was just honesty. I remember, I can still see it now, like proper trauma flashbacks, you know, like I counted the seconds on the clock and I'd be like, in a minute, I'll be dead. Like I won't have to do this for another minute. And I was counting the 60 seconds.

[00:39:50] And when it got round to the next 60 seconds, I'd say it again. I would just, it's literally just 60 more seconds and you'll be dead. And this nurse, my one-to-one nurse in intensive care being like, you're doing this to yourself. And it was because I was fat. Like the implication was that because it was a fat person.

[00:40:07] I couldn't breathe as well or, or whatever. And that I had done that to myself and that it was my fault, but I mean, ridiculously I crashed again about 20 minutes after that. And. I was intubated for two weeks in a coma. So I don't think I did that to myself quite, but is that sort of, that, that was the, that's the level of fatphobia that still exists in healthcare and it's no wonder people, fear, fatness, like, cause that's the reason fatphobia exists.

[00:40:37] Why? Because we're also horrible to fat people. Like of course nobody wants to be fat. Like it makes perfect sense, but it also creates a cycle of unimaginable harm for all communities.

[00:40:50] **Suriya:** Yeah, definitely. And I think it's, you know, to think about how fat people will go to the hospital and, you know, doctors just will not investigate some of the pain that they're having, because it's like, well, first of all, let's deal with the fatness.

[00:41:04] And it's like, like some like, like losing weight as well, like safely can be done overnight, which is also triggers the whole eating disorder culture. And then we'll, and then we'll, and then we'll give you a little tree of like doing the skeletons or whatever that's like really?

[00:41:19] **Imogen:** Yeah. It's really interesting.

[00:41:21] There was a study done a few years ago, actually. And they said that the health outcomes for people with certain BMI's were significantly worse. So basically the higher up the BMI chart UN um, the worse your health outcomes were, but when they did the research into it, it turned out that it was because you were treated so fucking appallingly.

[00:41:41] So for example, if I went to the doctor now was like, my legs are hurting. I think I've, you know, strained a muscle I've got done a sports injury or damage somewhere. I would immediately be referred for physiotherapy. I would potentially immediately be referred for scans or to see some kind of surgeon, whereas a fat person they're far less likely to go to the GP in the first place.

[00:42:01] So let's assume that they go three months after I go. Right. So the injury is already three months work. But it could have been because they were frightened to go to the GP in the first place. And then let's assume that the first thing the GP says is, well, come back in eight weeks when you've lost a bit of weight and see if it's better.

[00:42:19] So then there are another two months behind me in terms of recovery and then every single person that they meet after that is very possibly going to do a similar thing. Well, if you could just lose a bit of way, like you could very easily get to 18 months before anybody even actually assesses what is happening to your body because every single.

[00:42:40] At which you've interacted with somebody medical, their first suggestion is weight loss rather than treatment. Like the amount of times I've honestly, I've heard stories. Was it Bergey Taylor? I think maybe we're saying that she'd been to the doctor with tonsillitis. She had read like really raging tonsillitis and the doctor was like, can you get on the scales?

[00:42:58] And she was like, yeah, but it's my tonsils. And can you imagine, and the doctor just being like, yeah, but we are going to need to weigh you. And then like literally started like a weight loss challenge was like, the thing is right. My tonsils, like, I'm just, I really. So it's just a tonsils. Can we just, just the antibiotics, if you don't mind, like I'll come back in a week, you know, and we can talk about the Buttner's if you're absolutely desperate, but right now, just the tonsils, if that's okay.

[00:43:27] I properly lived through the whole, um, benefits, scrounging scum. So, um, the daily mail really, really like properly, went in hard on disabled people when the welfare benefits were changed. Um, probably around 2009,

2010, I think. Um, and it, like, it was just horrific, like disabled people were completely thrown under the bus.

[00:43:51] Uh, we were all faking. Like we were all benefits, scrounging, scum. Like I genuinely lived in fear. I've still got friends who are reported for benefit fraud, at least a couple of times a year by their neighbors, because they're seen in the garden, like. Or whatever, you know, like I live my whole life being like, I just, oh.

[00:44:13] But if I do that, oh, they going to put me on the front of the daily mail, the, you know, like we

[00:44:17] **Suriya:** had that thought yesterday. So that's so funny. You said that. Cause I had my like text to say out to get my PRP, like reassess and I had like a dry happy for the whole week. Cause I was like, why is this happening?

[00:44:29] Have I done something that they're checking up on me and calling them being like what's happening? And then I was scared that I was talking to normally on the phone when I did that. Oh shit. Outside in the garden. And I thought, oh my God, they're going to hear the wind and then think faking it. And then yeah.

[00:44:46] And then it was like, cause I could recall my date of birth. I was just really like having. I panicked worried that like what I'm going to have this taken off me. And I was trying to research all the questions and check. I knew what I was talking about and all that kind of stuff. And then yesterday, when I had a bit of energy for also went for a walk and mean, literally had that thought of like, oh my God, what if someone knows me?

[00:45:09] I don't, no one would know me cause I I've just moved to this area. But I was like, what if someone knows me, it takes a picture of me and then sends it to the DWP and says, I know. Yeah. And I was thinking, so what, because I've this one day in the whole week, because I'm able to like walk to the shop. It means that it was, it's just, it just made me have stop and realize how much energy is on our minds all the time of having to be proving that we're sick enough to get support.

[00:45:38] And then also, but also, you know, trying to make peace and celebrate the fact of who we are. But then also. It's just a whole, it's just the paradox of it all is really, really

[00:45:50] **Imogen:** difficult because it's all performative. Right. So, because you have to perform being sick enough for the support in terms of like gang, um, health care.

[00:45:59] So in medicine often, like I know a lot of people who are like, well, I mean, if the pains are four, I'm probably going to say a six because otherwise they won't take me seriously performative. Then you have to perform for social care or your, like, if you get any kind of personal carers, like you have to your worst days, you have to perform for your benefits.

[00:46:18] Like, but then also you have to perform for the people around you that you're like a normal person, like a not sick person. Like then at what point do I just stop pretending and like find who, who I am. And, but honestly, honestly, I've been doing it so long. There are days I'm like, I have no. But I literally have not a fucking place.

[00:46:43] **Suriya:** Yeah. That's, that's, that's what, that's what I think. I think it's something that my mom always used to say to me, like, well, when you're not feeling well, why don't you just, just, you know, just, just rest.

[00:46:57] And then you, you know, I know you cared for me, you know, but there's no, well, there's no wild part of this story. Like I don't get well, like I'm always here. So if I rest of the time, I don't feel well. I'm never going to do anything. That's completely fine. But also I do kind of want to do some stuff. And then also if I do something yesterday, even people who are really close to you will say, oh, but.

[00:47:20] Feeling you, you're not feeling that right now. And it's like, oh, so what do I do? Like, do I just do so, you know, you have to constantly communicate to say, Hey, I know I look fine, but I'm actually feeling really ill right now. And like, so I'm probably gonna look to the desert and having to, because also like the way that you hold your face or body is, is kind of dissociated from yourself.

[00:47:43] I think grimacing in pain all the time you learn that you can't really do that because you're going to draw attention. And then there's this kind of stuff. Everybody wants that attention, but OCI, you kind of want people to know, but you don't want them to make a forced, but also, yeah,

[00:47:59] **Imogen:** this,

[00:48:02] **Suriya:** like often I'll go into the bus with my, my bus pass and I can see like, it's like the combination of being black, being young, all these things.

[00:48:10] And I'm looking at my bus fast and going on. And also my picture is like 10 years old. So they were all like, are you sure? Like, did you find this? It's like, yeah, Mitch, I'm disabled. Like don't know what you want me to say? Like a flag? No, no, no. What you want me to

[00:48:28] **Imogen:** get my superhero

[00:48:29] **Suriya:** Cape out? Literally just get what's at home.

[00:48:34] So yeah, they put the performance of your body inside, outside to yourself. Just the constant thing. Um,

[00:48:43] **Imogen:** the head fuck. There's a proper headfirst route is, and then also we're not allowed mental health conditions because we've only got physical health. You know what I mean? Like absolute worst nightmare is a doctor being like, yeah.

[00:48:57] But is it in your head though? Do you know what I mean? So then you're like, you're constantly like, but I'm saying, I mean, just to be clear, absolutely not saying like, if I was saying after everything I'd experienced. Psychopath, literally like how I could be saying after everything I've experienced, but like, no, not a thing, but equally Mufson look mad.

[00:49:21] Like muscles act bad, mad. Mustn't say mad things must acknowledge mean disorder too much. Like must be looking like I'm very much holding it together because if I'm not holding it together, like then all my symptoms will be in my head. And yeah, that is like another layer of on imaginable pressure. Like

[00:49:42] **Suriya:** probably.

[00:49:43] And I think when I was, when I, so when I was 17 and diagnosed and I said to the nurse, Is there any counseling that I can have? And she was like,

[00:49:56] well, in my head, I was thinking I'm a teenager and I'd just be diagnosed with this massive thing. I know. So, because it was like, they, they put it on me to decide whether to have my operation or not the Brain thing.

They were like, you kind of do it, but if you do it, you might be paralyzed. But also if you don't do it, you might be paralyzed.

[00:50:12] But also you probably shouldn't do it yet because you're not that bad. So probably wait a little bit further into that. So obviously I'm like there go in

[00:50:20] **Imogen:** the bags,

[00:50:22] **Suriya:** like, is there any counseling? I can have it. She really was baffled as to why. I mean, it was like, for me, I was like, well, I'd rather have a chat before I do have a breakdown, but I think in their head, they were like, just wait until you have your breakdown and then come and then we'll put a hundred percent.

[00:50:37] **Imogen:** Yeah. Yeah. Definitely. Like I, so I'm part of, um, gastroenterology is, is one of my like main teams. And one of the doctors were saying to me the other day, how would I feel about being like a peer support worker? And I'd like, I kind of get it. I understand. Right? Like we're a niche community and we, we're not that niche quite big ready, but, um, like getting support from other people.

[00:50:59] Like, I'm all about that. But actually the first thing I said to him was no mate, you need a psychologist on staff. Like peer support is one thing. But essentially what you're asking me to do there is be a psychologist for other people who are experiencing what I'm experiencing. And just because you think I'm holding it together, doesn't mean I am actually holding it together.

[00:51:19] I'm just very good at performing it in front of you. Thank you very much. And the only time that I ever said to him, I'm having a really hard time and I don't really know what to do about it. He literally was just like, that's a shame. I'm going to refer you to the psychiatric department. And I was like, okay, I get it.

[00:51:36] Like, there isn't anything else for him to refer me to because like talking therapy on the NHS, essentially, she just doesn't really exist. There. Isn't a psychologist on staff, despite the fact that there should be. So when does he, the psychiatrist? Yeah. Like okay. She, she was kinda nice, but also like she's used to dealing with like genuinely, you know, psychotic illness.

[00:51:58] And I was just like, the thing is, I'm just a bit sad. I'm like my eating disorder and I've just got all this shit happening and do you know what I mean? And she was just like, yeah. Like have you got schizophrenia? I mean, she's

just, she's a doctor of the mind and I, I didn't need a doctor of the mind. I needed somebody to show me compassion and, and just like chat to me about the shit that I was experiencing.

[00:52:23] Like, she was not the appropriate person at all. And after about six weeks, I was like, I think we're probably done here. Do you know what I mean? Like, this is not useful, but like why isn't there just psychology as part of all chronic long-term impairment. I just don't really understand that at all. Like the implication that we would just be fine at the end of all of their shit is like laughable, literally laughable.

[00:52:46] Yeah.

[00:52:46] **Suriya:** And there's, there's also like the hierarchy of illnesses isn't there where you see this. Right and illnesses, which have all the money and all the things and everything. And then it's like, okay, it's just really

[00:52:59] **Imogen:** not seeing it,

[00:53:05] **Suriya:** but yeah. That. So also, like it is that thing have also been like the charities that I tap into are so stretched and run by like someone who were like really nice and shit, like what for their like grubbing son or daughter, because they really want to change the world. And then we don't, you know, and then, but alternately, if they were funded better, if people cared more about that.

[00:53:30] And I think it's also what are seen as like the sexy illnesses. It's just a really bizarre thing to do, but like, just in the sense of like brainstorm stomach thing, Not like nobody wants to talk about that. Like it's gross and it's scary. I don't want to raise money for like poo things or like bowel things or any things I don't want to talk about that don't want to talk about Brain.

[00:53:52] Cause they'll set means you might look weird or be weird. Like, and I don't really want to think about that. But disabled

[00:53:56] **Imogen:** kid is honestly the cutest thing in the whole world. Anyone will buy you a wheelchair, like, yes, I need a wheelchair. Are you under 18? It's sold. Do you know what I mean? Like how, where do I, where do I sign up?

[00:54:07] I will give you all the money. Like the minute you turn 26, you're like, I still need a wheelchair. Anyone, anyone, anyone can anyone, same age still make some money.

[00:54:20] **Suriya:** So that's literally what happened when I like, so my jet, when you said about why different career and treated differently, it's like one of the first times I went into hospital seriously was when I was about 13, went into the children's ward, Tigger, everything all over everywhere.

[00:54:35] Creation. So good nurses, so nice, whatever, when I was, so when I was 17, went back in for the more major thing and I had to have my blood taken before pre-op or whatever. And I said, oh, have you got that cream? You know, they put on like that freight cream, that kind of makes you think. And she was like, no, you don't need that.

[00:54:55] And I said, she said, if you're not going to deal with this, you definitely not going to deal with the pain of the operation.

[00:55:02] **Music:** Oh my God.

[00:55:07] **Suriya:** Why would you say that to me? So that was interesting. I was like, okay. So I'm not something that people can be sorry for anymore. Then when I got in the wall, I was younger. Um, and also very interesting severely underweight at that point, because I couldn't keep anything down. So I think thought that I was younger than I was.

[00:55:25] So it was about my team probably looked about spot to about 16, 17, and so much sympathy then, oh my God, you're so young. It shouldn't be happen to you. But then when, when I'm going the years I, you know, go in again, you see people like less sympathy, more kind of why you ask him for stuff. Um, very kind of your inconvenience in us.

[00:55:47] And so it really made it. It's just really interesting knowing.

[00:55:58] **Imogen:** Um, I just, I think that COVID has really highlighted that there needs to be massive discussion about medical racism, like how that hasn't been picked up by the media. I genuinely have no idea because obviously at the beginning they were like, oh, it's worse among like Bain communities. And I think all the researchers, it must be genetic surely.

[00:56:19] And so then they did the research and we're like, oh guys, turns out not genetic, just medical racism, like ha like how has that not been a conversation? My mind is blown. Like all the times that we've talked about COVID and yet we, we can't honestly like it. I am so. Overwhelmingly angry about that situation, like how we are still, how we can still be carrying on medical practice as we are knowing what we know about medical racism.

[00:56:50] Now, honestly, like if they, if this doesn't change, how doctors are taught from the ground up, then like anti-racism work essentially doesn't exist. Like

[00:57:03] **Suriya:** just, and I think the thing is that people don't cause I'm going to do a talk for like, um, this organization a couple of weeks. And part of it is that they want to know how POC differently by, by COVID and it, so I was chatting about some, uh, friends and, and where they were saying.

[00:57:18] You know, you're constantly hearing these things from the news, like bang people are more likely today. We're more likely to do it. The blue there's no. So therefore we're rolling out this blah, blah, blah. It's just every day, by the way, you guys do this,

[00:57:39] it's really, really like, it's just a level of sadness of feeling like, okay, so you've got. Because if this giant piece of information came out about like, you know, CIS white men, it's like, man, I'm more likely to die from COVID. But also there's not like it would be just a massive thing. It would be, but it's just like this thing of like, yeah, by the way we find out that you gonna die more, but anyway, blah, blah, blah.

[00:58:04] And back onto the meeting, literally. And it's so it's just like, oh, to us to be. And that's where, how misinformation spreads as well. Cause then you get the other piece of being like, well, Bain people are more likely to come to his conspiracy theories. It's like, well, nothing is coming from the mainstream media.

[00:58:20] So what do you think is going to happen? Is people are going to try and find their own solutions. And then they all get to sit around, eat a bulb of garlic a day or whatever it might be, which also garlic is bad for you. So, you know, whatever. Um, so because it's like, well, no one else is telling me how do our community.

[00:58:37] Preventing. You're also telling us that it's our fault. It's like, it's your fault that you're going to die. So then we're like, oh great. So should we do more issues?

[00:58:45] **Imogen:** Yeah. Yeah. But I mean, it's sort of similar to those like cycles of negative behavior. Like you're reinforced so negatively in every interaction.

[00:58:56] Why would you go to that? It's very similar to that. The one I was saying earlier about the BMI and fat people going three months later with their injury, because they know that they're going to be treated badly as a result of their fatness. Like, it must be very similar knowing that your GP is potentially going to treat you poorly because you're a black person or person of color.

[00:59:16] And then every interaction after that, just being the same again, like that negative re. RI, what do I mean when it's just reaffirmed, that'd be game constantly that like you're lesser for some reason, like

[00:59:31] **Suriya:** people are, aren't treated well by the medical industry, especially black people, especially, especially black women.

[00:59:37] How many black women have died over? COVID like in terms of like parents and people giving birth, it's still one in four women, black women are likely to die in childbirth

[00:59:49] **Imogen:** in the UK. Hello,

[00:59:58] **Suriya:** it's heavy, man. It's like heavy every day. Something reaffirming stuff that we already knew now in stats, but then no solution for it. Just kind

[01:00:09] **Imogen:** of. Yeah, a hundred percent, but then also when you go into those, um, situations, which you have to do regularly, because you have absolutely no choice about it.

[01:00:20] Like, there's that fear constantly that you can't be the angry black woman. Like you, you can't like you're, there's this, like, you have to be performatively nice. Like you ha you're allowed to advocate yourself, but only to a certain extent, if you really push boundaries or appear to be angry, then you know that your treatment is going to be curtailed as a result of it.

[01:00:41] Like it, it's just another way in which your restrained and oppressed in a situation where actually you should be able to say make that is absolutely not good enough. And, and I absolutely do have the freedom to do that. Like obviously angry, disabled person exists, but not in the same vein at all. Like I can absolutely go into a room and be.

[01:01:01] No mate. Absolutely. No. Like, um, I'm angry about that and this is why, and here are my reasons and you will hear me speak. And I know that my treatment is unlikely to be affected as a result of it, but my best may, absolutely

not. Like she could not go into a room like I could and be angry like that because people would be frightened of her in a way that they would not be frightened of me and her treatment would absolutely be altered as a result of it.

[01:01:27] So of course she doesn't get decent treatment. Of course she fears going into every room. Of course she doesn't understand what's happening with her impairment because she's too terrified to fucking ask anybody. Like it's so wildly different.

[01:01:41] **Suriya:** It's so stressful. I think the last, my last one of my last experiences, if they switch on now, just unlocking the memory of.

[01:01:48] Um, when I had the last operation I had a couple of years ago, my wound was healing, healing footing, like in a weird way. And I went to a doctor and he told me that it was infected when it wasn't. But, um, so the whole night I was having this panic attack that I, cause I felt really tired and really sick.

[01:02:06] And I was like, I must I'm I'm I'm having like I'm in septic shock. I am. I know. I am like, cause I was really like, and actually I was having this really intense panic attack. It turned out is fine. Went to another doctor and he was like, no, no, no, it's it's actually healing fine. It was, um, it is fine. But I think what happens is that they only have the physical measure of what it looks like on white skin.

[01:02:27] So actually they didn't know what a wound was. This guy was so used to and then actually I'm black skin and I didn't have any reference. Cause even when I was Googling it, like none of my skin tone was coming up to say how it was meant to be healing. And then I'm like, it was just, it's just like made me realize.

[01:02:46] Oh shit. Like I'm it? Yeah. It just, and the only reason that that was how I happened to be resolved properly was because there wasn't enough beds in the NHS hospitals. So they had to like, you know, when there's a conduit sometimes to the private hospitals go to private hospitals. So I happened to get this private health care.

[01:03:04] So if I hadn't got the private house health care, I would have been only able to go to the NHS walk-in center, which meant that the, in this doctor who very flippantly just went. Yeah. And I'm like, what? Like, I've got an open rude, like I must say it was really, really like you were affected. And obviously then I'm feeling hot, I'm feeling and I'm like, oh my God, I'm going into shock.

[01:03:26] And then not care about me and they just want me to die. But, um, so that was just a moment where I was like, oh wow, like I'm really scared. What have you done for the rest of the day? It's the day holding for you? Oh, I'm wall-to-wall

[01:03:41] **Imogen:** with, uh, sitting down really very busy, very busy schedule of

[01:03:46] **Suriya:** sitting down.

[01:03:48] That's a bit of me that is that we'll be setting on

[01:03:51] **Imogen:** the list. This is sitting down every single one of those. Just sit

[01:03:58] **Suriya:** still. That is a very fancy to do list. I'm impressed. Oh my gosh. You've tried so much. It's been, it's been great. It's been so good. Thank you so much. Um, yes, they welcome.