

[00:00:00] **Jenica:** And it was like, everything was brand new being while we're here. We've been staying inside for this long, like, are you guys okay? You don't have to FaceTime me every day.

[00:00:23] **Suriya:** Welcome to Sickbabe, the podcast from my bed to yours. Hey, 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 tide sex to Mary on Facebook, who thinks she knows more about your condition than you do.

[00:00:41] 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.

[00:00:58] All right, let's get into it. Hey Sickbabe. So today I spoke to Janique and Leah, who is an author. Publisher sickle cell activist and campaigner. And we had a really cool combo about working whilst you're sick. How do you still balance that idea of being ambitious, but also. Try and listen to your body. I really hope that you enjoy this combo as much as I did.

[00:01:27] Okay. Let's get into it. Do you feel that there's a bit of a combination as well about being sick and like being this multihyphenate like doing different things?

[00:01:38] **Jenica:** Definitely because I feel like it's almost like. There's a, me that lives in another world. Who's very healthy. And she's the one that comes up with all these ideas of all the things that Jen is going to do.

[00:01:50] And then I'm just here, like, how are we going to make this work? But, you know, I'm always trying to, I'm always doing my best to kind of do all the things that are on my list. And it's a lot of it is helping other people as well. Yeah.

[00:02:06] **Suriya:** Yeah, because that kind of drives a lot for your work. Doesn't it? Cause obviously you're an author, you've written these amazing children's books.

[00:02:14] And do you want to talk a little bit about that? Like your experience of, of kind of why, what, what led you to want to write those books?

[00:02:22] **Jenica:** Lee? My, the children's books that I've written, they are all about SQL cell, which is a condition that I live with. For myself as a child growing up, I didn't really understand my condition.

[00:02:36] So I grew up in isolation. I was just a lot of it was confusion because I didn't understand what it was. I couldn't like tell other people how I was feeling, what was going on. And. Once I got into my adult years looking back, I just think, gosh, I wish I had something that would have made my childhood different, that childhood experience of growing up with a condition that was, you know, had a good, a real impact on my life at the time.

[00:03:05] I wish I had something that would make it different or that would help me to understand. And then I just thought he, you gotta be the change. So I wrote a children's book about sickle cell. So the main kinds of the overall. The overall goal of the CVS. Cause there's two at the minute and I plan to do a few more.

[00:03:24] Is to give children with sickle cell, the confidence to speak about their condition openly and confidently, and, you know, tell their friends, this is what I've got to do to stay well. And this is what, the things that I have to do when I'm, you know, missing school or sometimes when I'm off, like it doesn't have to be something that we shy away from.

[00:03:43] And I also think that's, you know, people having a stigma against something as well, just. I always think that when people have a stigma against the conditioner, it's because they don't understand that it's not really about you. So as long as your, you have that confidence, you understand what is it you're going through.

[00:04:00] Life will be different. And that is just what I. That's just what I wanted for the books. So it was like motivated by myself, but for the children growing up today with sickle-cell just, you know,

[00:04:14] **Suriya:** it's just, just amazing. And I think that that's like a specific kind of experience as well of being, um, being sick as a child as well into adulthood and the transition of that and the acceptance of that, and like actually realizing.

[00:04:30] Yeah. I feel like as I've got older, I've realized them the stigma that still exists around so many sickness and disability and, you know, sometimes you think, oh, well we're like forward, like we're forward thinking and we're like, we've we've progressed. But actually when you really speak to parents and

children and young people who are living with long-term conditions, Disability, just this needs to be still at fault for the things that we fight for, because the support that is needed for young people and children is, is, is still, there's still so much to go.

[00:05:03] And that thing of, like you said, like that isolation of like, oh yeah, you know what it is is, we'll just kind of put you aside and yeah, you'll miss that as a school and you just won't get it. And like, you can't do this and we'll re like wrap you up and say that probably your life is going to be like smaller insurer and all these different things.

[00:05:18] And it's like, as the. That's just what you got to accept really, um, amazing to see. Just the stuff that you're saying, like you, you can live your life in various different ways. And the more you know about yourself, the better you can make the choices 100%.

[00:05:37] **Jenica:** And I think that's also probably why, you know, in, in my mind, there's so many things that the things that I want to do, it's like for me, I, I want to make sure that I achieve them.

[00:05:48] That doesn't have to be no time restrictions on them, but just to show them. Hey, you can do this and you can do that. And it's not even about proving people wrong. It's just about proving myself, right? Like prove it to myself. That log knew I could do this, even though you guys

[00:06:02] **Suriya:** are like,

[00:06:02] **Jenica:** whatever, I it's for me, it's not for anyone else.

[00:06:06] Do you know what I mean? But the example that I'm setting by doing that is that, you know, you guys can dream big. You guys can, anything you want to do. Like you don't have to feel like you have to

[00:06:17] **Suriya:** be stuck. This is us. Yeah. Wow. How do you balance, do you think that thing of being like a very ambitious person and wanting to do so many things like you were saying before about like there's a, in your head sometimes there's this like Jamaica that lives by the quote unquote healthy and then the reality.

[00:06:37] And obviously we know like being a sick baby and stuff. The idea of overcoming your sickness is not ever a reality because you never try to overcome it. You're trying to. With it or alongside it, but sometimes I know that

we probably get, oh, I just wish like, you know, you have, like you said, you have that image.

[00:06:57] How do you balance those things together? Do you know what

[00:07:00] **Jenica:** I have those moments I have that, gosh, I wish I could just keep going or I wish, you know, I wish I weren't so tired right now. Um, I have a long list. And I know this is going to sound crazy, but ticking things off that list, whether I, whether it's been on the list for one year, five years, seven years, that is just how I'd go about it.

[00:07:24] I think to my list, once you get on the list, It's going to be done by the grace of God, by prayer, by, I don't even know what by sleep most of the time, but, um, yeah, I just, once it's, what, if something gets onto my list, it's something that I know that I'm going to get to. And I very much, one, one thing.

[00:07:44] Don't do. And I really kind of, I, I practice a lot of mindfulness or meditation I try to is to not focus on anybody else, because I think that is the biggest distraction and the biggest setback. Sometimes within our own minds, we look at everyone else and, you know, everybody has probably that. For one, they're probably not Sickbabe they normally don't have a chronic illness.

[00:08:09] They're probably not tired as much as, as much as I am. And it's, that can then make me feel like, oh my gosh, I'm not, I'm not working hard enough. I'm not doing enough. And I am hard on myself, but at the same time, I just. Reflection is everything. So not looking at anybody else and just focusing on my own journey.

[00:08:26] Like I'm the only person in the world, and these are all the things that I've done already. So therefore I'm still going to be able to do all of these things as well.

[00:08:34] **Suriya:** And I love that mindset. And I think that that comparison piece is so important. Isn't it? Because in general they say comparison is the theft of joy.

[00:08:43] Well, I feel like as a sick baby, it's like comparison can be the theft of your house actually, or comparison can be the theft of your energy because the fact of like you, we overstretching or push them further or not listening to our body has it, has, it has a detrimental effect. And I think, I think we've probably all been through phases.

[00:09:04] I know I've been through, um, the phase of like maybe. We often say about like, you know, you go through stages of grief when you are, when you're diagnosed or when you, even if you're diagnosed from, from young, when you have the reality of how it manifests in your life as an adult, there's like a new stages of grief, I think.

[00:09:24] And then it's like, Within that in the same way that if somebody dies or, you know, you lose a job or lots of different things, the reality of accepting that comes with those stages of grief. So the denial, the anger, the frustration, and it's not a linear thing, you know, you're not going through 1, 2, 3, 4, 5, you going back and forth between these things.

[00:09:47] And I think that denial bit makes you, I know I went through, when I was diagnosed, it was. Okay, cool. Anyway, I'm going to currently live in like it's like I've got like, um, able-bodied none of the law and nobody can stop me. Um, because I'm a, I'm kind of a recovering perfectionist as well. It's the balance of.

[00:10:11] In praise and imperfection becomes a whole new thing when you a Sickbabe and also the idea of you have to, um, kind of think so I'm in, but I'm embracing imperfection, which is one thing. And also I have to realize that things are not going to be done on the timescale. I want to do them, but it's like, like you said, you've got that dual personality.

[00:10:35] Pardon me, what's it like this? Then you have the reality or your body speaks to you in new ways and it says, Hmm, know how well that's gonna, that's going to go down. So I think, I think it's, it's really interesting. The whole idea. Of comparing yourself to others and, and, and making the difference between something that Bernay brown says, which is like perfectionism isn't necessarily like healthy, striving, like healthy, striving being an ambitious person is okay.

[00:11:05] But when you tip over into perfectionism, that's when it becomes really challenging. And I think for me as a disabled person, it's like accepting that I can still be, I can still strive. I can still have ambitions. I can still. Um, things done, but I think I loved what you said about having this list, but sometimes the things on the list will take me 10 years to do, and I don't measure that.

[00:11:28] No.

[00:11:29] **Jenica:** And do you know what I also think is it, this might sound completely weird, but like the, the, the life expectancy for someone that lives with sickle cell at the moment is something like 40 something, 40 to 45, something like that. Anyway. So. There's also this thing of, you know, the shorter life, you gotta live it, like it's your last and all that.

[00:11:51] But me having something on my list and having like a long-term goal, it makes me feel like I'm not restricted to that. What, what they're saying to me. So I just, it just, it gives me that feeling like it's all right, I've got time. Whether that is the truth or not, no one actually knows anyway, like, yeah, okay.

[00:12:08] I have this condition. You guys are predicting this, but someone can step out someone complete. They can step out of their house and not return. Do you know what I mean? Nobody knows what the future holds. So giving myself these things where it said, you know what, I might do that when I'm that age or if that's something I want to do when I'm that age, it's just given me that, okay, I'm looking forward to getting to that age.

[00:12:28] You know what I mean? It's just, it just gives me that, but also what you were saying about the whole. Stages of, you know, going back to grief and going back to acceptance and then follow it all the way back to like, you know, deny. And that is so real. I feel like every time I have a setback, it's like I have to go overcome all of those stages again.

[00:12:52] And. That's also, those are the things that people probably don't even realize as well. You know, some people might overcome something and then, and they're just, they're just good. They're good for a period of time. Whereas I've always got to be considering, oh my gosh, what about this? I'm like, gosh, what about that?

[00:13:08] And

[00:13:09] **Suriya:** yeah. I think we love to think about like, binaries that we it's like, I'm sick or I'm not sick, or I'm like, I'm in, I'm like in it deeply or I'm over it. And it's like, actually in many things in life, it's always like a process and actually the kind of place that you're in rather than. Uh, like rather than the it's it's it's, um, this or that, it's like, I'm probably always going to be carrying grief with

[00:13:38] **Jenica:** me all of that, all of the time.

[00:13:42] And these can be things that throughout a day, you know, depending on what you think about or something like that, I can look back at, I look back at things like I did. Um, I launched my book in 2020 just before COVID. And the debate between am I going to cancel the launch? What am I going to do the launch?

[00:14:02] Because I had to have surgery. And I was absolutely exhausted. I'm not really going to do a launch three weeks after having surgery at a UMass, like, but then still doing it and looking back at the pictures and knowing how I felt at that time compared to how I'm feeling now, I can still like speaking about it.

[00:14:19] I can get emotional about it. You know what I mean? So I can. We can always go through these experiences. It's not even like over a period of time. It can be all in one day for us. Um, and still just overcoming and still just being here. I find just being in the present moment and accepting how I am right here right now is like my new thing that's working for me.

[00:14:43] So like, okay. Right now, um, you know, I'm feeling like shit is all right though, Jen, you know, you've allowed to shut the laptop

[00:14:53] **Suriya:** set off the phone. Exactly. It's

[00:14:57] **Jenica:** okay. Um, You know, um, I just think now I used to battle with myself about feeding like this and feeling like that. And I've got to stay positive.

[00:15:08] I've got to keep going. And now I'm just like, do you know what feel shit? Because shit, if I'm tired, I'm tired. If I don't want to speak to no one, I just don't wanna speak to no one. These are. Is it just things that it just helps me to just process and just be my normal,

[00:15:24] **Suriya:** you know, th that's, that's such a big thing, isn't it?

[00:15:27] Like I normal is it's just, even from one sick person to the other, even one person to the next person with sickle cell or, you know what I mean? It's like, everybody really has to find their own pace. And I think what you said. About mindfulness is funny to me because I feel like, you know, when you finally get diagnosed, they give you a pamphlet.

[00:15:45] It's also like, where are you at? You know, I love these apps and you're like, oh, mindfulness and green tea is not going to change me. But then

as you get older, you're like, maybe I will pick up that mindfulness. And it's like, and then, and then you could months later in life, the mindfulness, the idea of Asia style.

[00:16:00] Oh, please be quiet. But then, so it's even that it's like the coping mechanisms change depending on where you're at, but I think, you know, the idea of staying. He, uh, is, is, is as much as we might be like, oh, please stop doing, you know, you know, the whole wellness industry has a kind of mindfulness in a way that is sometimes a little bit toxic, but, you know, for people who were, like you said, having to think about death or think about, um, Mortality on a regular basis in a way that I think is different to those people.

[00:16:33] Who've never experienced sickness because I think COVID, and I'm wanting to ask you about this. How have you felt about the reality of a lot of people talking about sickness and health and stuff in the wider thing? I, for me, it's been illuminating, but I'm interested in, I mean,

[00:16:51] **Jenica:** for the, for those of you listening, I rolled my eyes.

[00:16:54] So.

[00:16:59] It's it's unbelievable. I just think the world is unbelievable. That's all like a, COVID just showed me a different side to people and society and the whole health industry and everything. And it was like, everything was brand new being while we're here. We've been staying inside for this long and you guys, okay.

[00:17:26] You don't have to FaceTime me every day.

[00:17:31] **Suriya:** Like not my mental health. I've been living this literally. It's like, whatever was in the hospital. You didn't say stop me every day. Now it's like zoom, zoom, drinks, listen.

[00:17:45] **Jenica:** And then when you don't answer, babe, just want to just want to chat. Everything's fine. You know?

[00:17:51] **Suriya:** When I

[00:17:52] **Jenica:** was like

[00:17:53] **Suriya:** they said, and when I actually probably maybe needed you to be aware of things, I think it's, yeah, that's the thing for me.

[00:18:01] I'm like, I think there's, there's been a lot of people, chronically ill people and disabled people who've expressed similar feelings about. Hang on a second. When we having to have challenges like this one, we trying to ask for things like remotely and, and obviously there's that side of it. But for me, it's been the interest in, um, interesting to see how on a whole, as a site, we battle with mortality.

[00:18:28] Um, just in a sense of, of course, like. The reality of COVID and losing people to COVID in a way that feels so, you know, volatile and invasive and stressful, like it's really, um, you know, it's so it's so traumatizing and also there's a sense, there's a sense of, for those who are unlike, you know, other spectrums of, of seeing people who.

[00:18:53] Maybe, you know, I'm not going to go into extremes of like anti masters or, or people who are in like the COVID denier box, or even people throw in, in the middle of feeling like, you know, it's mind over matter or this, that the other. And it's like, oh, you really, you really think that you could control your body in it.

[00:19:10] Like you can control. The way that we are, or when you live or die or you're thinking about is, and I know that obviously for survival, we kind of have to have an element of denial because if you really thought about that, you know, existential dread is real, but he made me realize of like, like you were saying before, You know, when you have you been in pain for so long and then you're not in pain and you realize, oh, I was in pain for that long.

[00:19:32] I think it made me realize how normalized it is for, you know, for us guys who are chronically ill or disabled and talking about like life expectancy or death or thinking about those things. It's like, like in a way it felt like. I know a lot of people talk about disability, just this being one of the things that will be part of our survival that everybody needs to adapt.

[00:19:53] It's not just disabled people because the idea of a lot of sick people at the moment, yes, it was stressful. But in a way, we we've gone through a lot of grief stages, a lot of adaptations of having to live inside. A lot of reality of thinking that we are at risk and our immune systems are not like, you know, able to tell everything.

[00:20:12] So the adaptation was. Different. I think, I don't know if you've felt that like

[00:20:18] **Jenica:** yeah, I did in a way. Um, do you know what I honestly think, I know, obviously, you know, that I spent quite a bit of time away from the UK. Like, I feel like that was good for me. Cause I feel like my college experience was just.

[00:20:38] I'm not saying that it would have been great because I think it was terrible for everyone, but it was very much, um, I think that my COVID experience was just. Negative in a way that I was, it just highlighted certain things to me. I was also, um, like I was in hospital throughout a period of that time in and out and in and out for a period of time as well.

[00:21:04] And even things like the NHS, the, you know, the doctors, the hospitals, how, how all of that

[00:21:10] **Suriya:** worked. Yeah. Yeah. We probably don't know

[00:21:20] anybody is sitting listening to this. It's like knows exactly what that sound means. It's just like it's too much. Yeah. It's like, yeah, we, yeah. It's like, that's a new grief in and of itself. I think the reality of, of, of, of how the NHS.

[00:21:41] You talked a little bit on like the stigmas and the, the, um, experiences that we have with others. When talking about our experiences of being kind of also, which is. Um, component of sick babies, those who are living with invisible conditions and disabilities and illnesses. And we were talking a little bit before about the experience of like tiredness and like what it means to, um, So when we there's tide, this is one aspect of like, when you say you're tied to someone and someone says, oh yeah, I've been, I've been tired as well.

[00:22:19] And it's like, I don't really think we're talking about the same thing, but also the idea of. Um, kind of there's a balance, isn't it? In terms of, like you said, not feeling like you want something to consume you to the point that you feel like you have no ownership over your body in any way and, and, and ownership over how you feel and are in yourself.

[00:22:42] And then there's also the side of it where you feel like you have. Oh, and these things again, because you're like, actually, no, no, I am saying like, don't tell me, you know, it's a weird thing of actually trying to, for me celebrate the fact that I'm sick or celebrate the sick bay, which is something that I feel like goes against everything that we've asked society has raised us in.

[00:23:05] And like how, like what do you, how do you feel about that kind of stuff?

[00:23:09] **Jenica:** I hear you with that one because. In one sense. I feel like, oh, you know, don't bring attention to yourself or don't, you know that, but then at the same time, it's like, no, it's, I'm sick. And I'm like, it's okay. I'm allowed to be, you know, and I hear that.

[00:23:28] And some, I think I've learned. Um, accountability and acceptance those two going together because sometimes I would, you know, I would keep going and keep going. And then when it, you know, when it's just like, you, you can't go no more and you've completely burnt out and there's nothing left you, then start to you.

[00:23:51] Got you. Then get into that mode of feeling. Sorry for yourself. Why me? Why is this happening? And so learning that, do you know what? I can't do that? Like, it's not good for me, not so much. I can't, I can, if I want those consequences, but it's not good for me to do that and being okay with that,

[00:24:13] **Suriya:** like I just like tired is my thing.

[00:24:18] That's like, put it on a t-shirt kind of thing. You know, I'm

[00:24:24] **Jenica:** sometimes like, There's people around you that tell, you know, if you keep saying that that's how you're going to feel. And I'm like, no, no, but it is how I feel. This is not like a law of attraction thing. This is like, I was, I was born with it thing

[00:24:41] **Suriya:** wrong.

[00:24:41] Hashtag babies is literally, I was born with it. I wasn't born with it. Like my oxygen levels are actually low. Like I am, my blood cells are actually. I think, I bet you know, this is not

[00:24:58] **Jenica:** that, so yeah, I think I'm in that, in that whole stage of do you some, sorry, I've completely, this is like sticker pin as, as my granny would say, but do you sometimes get that people are engaged the whole glamorizing.

[00:25:19] This, any of, you know, even, even the name of the pod Sickbabe pub there's, there's other, other like disabled things where it's like, okay, I'm disabled and I'm proud. I'm chronically ill and I'm proud. And then I feel like

there's the other side of people that are just like, no, no, no. Like you don't have to, you don't have to put disabled in the title.

[00:25:40] Just be this and not be disabled. So it's like, there's a battle between highlighting the fact that I'm doing this and I'm chronically ill or I'm just doing this anyway. It doesn't matter that I'm chronically ill. Yeah. Battle.

[00:25:55] **Suriya:** Yeah. It's um, it's really difficult, isn't it? Because sometimes you are. I want to like, you know, you said you are, I want to, I walk into.

[00:26:02] And if I walk into room on first glance, nobody's going to know that I'm sick. And sometimes I want to walk into that room and I do want to feel like, let me just daydream for a second, that I'm not sick. And I'm just like, people are going to respond to me. And it is what it is. And these people in this moment don't necessarily need to know.

[00:26:19] But then there's other times where I'm like, I want you to know on a political level, because I want to contribute to the conversation about sick. People are all around you. People are dealing with lots of different health conditions, disability, things that you literally don't know. And actually, if I can enable that, if I say ban sick and you realize that.

[00:26:39] Oh, I really didn't. You didn't, I wouldn't have suspected that at all, you kind of eat challenges in your mind that lots of you don't know what people are dealing with, so don't assume. And then there's another side of it. It's like, actually I do need to disclose because I have access needs that like, I don't want you to ignore so, but I feel like I flipped between all of those three all the time.

[00:27:01] And I think it's interesting. Cause I was talking to another friend the other day and they were talking about. Um, dating actually. And they were talking about whether they wanted to put it on their bio and their dating bio that they were disabled. Um, they have like a physical and, you know, when you meet them, you Mark, you know, there are certain kind of, um, ways that their body moves, that you might not like pick upon the fact that they have some sort of condition, but obviously before that they are, do they need to disclose it?

[00:27:29] Do they want to disclose it? And it was interesting cause it made me reflect on, I think it's that thing again where it's always inflows and it's like I can decide today. The I'm going to tell you every iota of all the experiences I've been in hospital, and then tomorrow, actually I can decide that I'm not going to share that part of myself with you.

[00:27:48] And I don't really want to, because I'm in a different place. Maybe I'm being more sensitive about it. Maybe I'm still working through certain things, but I do think, um, you know, I'm of the belief that. If you're living with a chronic illness, if you're living with a disability, you don't want to disclose it.

[00:28:05] And that's your thing. That's like your decision at the same time. I do question when it pops up in myself, how much of that is important by denial? How much of that is informed by shame? How much of that is informed by stigma that I've internalized. So unpicking those things. It's like, if it's genuinely, like, I just don't want nobody to know my business, but I mean, that's one thing, but if it's like, oh, I feel like they are going to.

[00:28:30] Judge me. I feel like it. So basically I think it's a lifelong journey of like

[00:28:35] **Jenica:** per situation, every situation, every kind of encounter how, how it's going to be. I feel like up until the age of 25, for me, it was like, Oh, this is the secret. Oh, everybody doesn't need to know if I don't tell them, they won't know.

[00:28:56] She want to be at that TikTok. Who's gonna know. No one's gonna know. No one's gonna know. And then like, you know, I end up in hospital or one time it was, I was at work and ended up going into a crisis and I collapsed and everyone's like, what? So, I, I feel like sometimes in some spaces it's important, but I also think it's down to the individual as well.

[00:29:21] Um, I like to, I think I'm more of a share now. And like you said, on picking the reasons why I may go into a space or be in a situation where I think I don't want them to know and being in my head and being like, okay, why not? Is it because of this? Is it because of. Is it, you know, but I really do feel like the only way, especially with sickle cell, because it's something that affects a lot, you know, majority of the black community.

[00:29:51] And it's something that people need to be aware of in order to not kind of continue the cycle. I have it in my head that Jen is important just to speak about it. Like, it doesn't matter that that's just for me and that, that condition, but there are times where sometimes I don't. Yeah, you sometimes, you know where the conversation's going to lead.

[00:30:15] To have this conversation.

[00:30:17] **Suriya:** She should leave me. Literally. I haven't got the energy to deal with. Oh my gosh. Look at these different you're like, okay, let me just pull up a presentation from my mind. All the things I know this sounds to me, like I just want to like, watch this show or like eat my piece of cake.

[00:30:40] **Jenica:** In peace, but the reason why I think I've gotten to that, that stage of always sharing is because sometimes it will then come up. And I think again, you know, people, oh my gosh, I didn't know. I'm my gosh. You never mentioned, oh my gosh, you didn't tell me, like, then it's also on me to have that responsibility of, you know, then you battle, we shouldn't have to, you know, all of that stuff.

[00:31:06] So, um, yeah, I think in. Paul sent some open, but yeah, that's the individual survey. We completely went off topic there, but

[00:31:14] **Suriya:** just to go off into like, honestly, the balance between how do you, you know, language, how do you talk about yourself? How to other people talk about you? I think it was so powerful in the community.

[00:31:26] I know that I've shades of people who are like, you know, like the chronic illness warriors has hashtag and it's like, for me, That's not okay. That one's not for me. I mean, it's up to me, but then again on pick your, my kind of judgment error areas of me or the shame areas of me, of like, w w why you bump, if somebody else needs to use that statement for themselves to empower themselves, then that's what they use.

[00:31:52] And you know what I mean, people will look at my, like you said, like Sickbabe and go, oh gosh, I wouldn't use that for me. That doesn't feel right. And like, at certain times, like, I've got a lot of power. That kind of hashtag warrior every, I don't like the, I don't like the, I don't tend to like battle terminology because you know, you can't win or lose synchronicity.

[00:32:12] You just, you just, it is what it is. You know what I mean? And I think feeds into this idea of like what you do. You can help it, you can change that and things that might less than certain things will also, you'll never know. Sometimes you will do everything right, and you'll still have a flare up. You'll still have a crisis.

[00:32:27] So I think it's important that people know. You know, there's, there's, there's sensitivity around that word, but you know, all the times when you're going through, you're either advocating for yourself with healthcare systems or

you are trying to like celebrate yourself with, so it feels like about all some times.

[00:32:43] So actually that language might feel appropriate for certain people at that time. Um, but then other people find it really dehumanizing and then some people find, you know, for me, embracing disability has been a new thing that is like, Before, you know, it really was seen as something like you, you realize how much stigma is around that word.

[00:33:06] If it's seen as like you're less able or whatever people feel that. But then for me it was like, okay, but I feel like embracing out this moment is political. Statement like I need, you know, actually society has disabled me by the inaccessible ways that it is. And also I think that, like you said, the visual idea idea of who, what a disabled person is and who they look like.

[00:33:36] Can't just be as one type of idea. And especially for black women who often it's like. You've gotta be strong. You've got to hold it together. Do you know? I mean, so actually to be like, yeah, I am like, like disabled and I'm like, we can like parts of me. Don't really like show up my buddy. Doesn't always show up for me in the,

[00:34:00] **Jenica:** I hear that so much.

[00:34:02] I'm now at the stage where I just do you

[00:34:05] **Suriya:** know what? It's just

[00:34:07] **Jenica:** a word. This is how I have to think about it. This is a word. Society has used to describe someone. Who is like me, but like me is, is like, there's a whole syllabus. Do you know what I mean? There's a lot of a soul like me. Like you like somebody else who has sickle cell who probably has more, um, difficulties, mobility issues, then me that there's lots of different ones, but this is just the word.

[00:34:36] And again, it's just about, yeah. Okay. We can fight it to say, oh, you know, Disabled because I'm still able to do things and empowerment. And I get that. I hear it so loud and clear, but at the same time, it's about okay, if this is the word that you're going to pin on me, I'm going to then show you what this word looks like to me and to that person and for that person.

[00:34:58] So it's not just, you know, the painting of the wheelchair in the car park because I'm, I'm going to pull up and I'm going to step out of my car, but.

By the time I've taken two steps, I'm out of breath. So I'm not parking all the way over there. You know what I mean? And this is what I look like. So the, this is my disabled, this is my version of disabled.

[00:35:19] So I'm taking your words and I'm showing you what it is to me or what, what, what I am, where I fit in that word. Yeah. And sometimes we just can't fight the system. We just got to kind of. I don't know, use it against them.

[00:35:35] **Suriya:** It's that thing it's like, we use language is redefining. And even like over the last few years, I found it really empowering when I've gone to places.

[00:35:43] Um, cause I've got like my little radar key, um, for the kind of accessible toilets and stuff. Cause sometimes, you know, my body goes into different places often and like when it, when I go to the places that have the light. Um, by John there, that's like, not all disabilities are visible. I'm like, you know, I don't, I'm not normally a person who's like moved by and saying things, but actually I didn't start getting, like, hadn't realized how much tension I was holding about a thing until I saw some thing that felt like this is relieving.

[00:36:15] That it's five relief. Yeah. It's relieving because I did actually have an experience once where I was in. And, uh, like what came out of a disabled toilet and this woman like literally shouted at me in front of everybody being like, you know, you need to leave that for people who really need it. And dah, dah, dah, dah, dah.

[00:36:31] And it really shook me because I think when you are living in your body and you're like, I'm tired, I'm in pain, I'm busy. So if I go into one of them cubicles, I might drop out and there's lots of things on need. I know, so one of the really needs to justify it to anyone. I was put that moment of like coming out, being like, I can't have just had been able to do what I need to do as a human media and not be in any kind of pain or, or worry, and then to step out and be like, yeah, It's like, wow.

[00:37:01] Like, that's really that, like, sometimes you forget in it, you know what I mean? You forget, you forget that you people can't see what you're dealing with. Um, so having those moments that if I walked out and then people see a little badge that says not every disability is visible, it's like, That really enables me to feel, um, safe in that moment.

[00:37:22] **Jenica:** Yes. Also what you're saying about sometimes you forget that they don't know, like if I'm feeling unwell, it's almost as if. I feel like

everyone can, like, I feel because I feel so bad. I feel like they must, they must know. Or I just forget that actually I still look fine. No, don't I, and um, yeah, that's, that's crazy.

[00:37:45] I've had that been attacked as you come out again and you're just like, you're not even prepared. It's like, you wasn't even ready for the battle and

[00:37:55] **Suriya:** yeah. I mean, so I feel like in those moments, it reminds me why it's important that I speak out about my experiences, because I'm like, okay, You know, what if this means that in 10 years time, people are going to be so used to the idea of like people literally deal with so many different things that you have no idea about on them and the house industry as well.

[00:38:17] The way that capitalism is in is infiltrated every areas of our life. And the fact that the ones that you hear loads about, you know, competency on white supremacy, the wa the, the conditions that you hear loads about. It's not because those are the only ones that exist, or those are the only ones that are the most quote, unquote serious look like, like he said, sickle cell is, um, a kind of in the, the lack of awareness funding is largely impacted by the fact that it affects black people.

[00:38:46] So you know why, so we can't be, and actually Lee, even over the time of kind of meeting you and reading more about sickle cell, it's like, Well, how is this ever being seen as though it's like something? Cause when I grew up, when I was a child, it was like, people would say, oh yeah,

[00:39:09] but sickle cell. And I just literally thought, okay, it's just like, Like in anemia, that's the way the April's kind of phrased like, oh, they got to take a couple of tablets and they'll be fine. But like now learning about like the crisis and like you said, the life expectancy and these things, it's like, oh my gosh, like this kind of awareness is really been a victim to white supremacy.

[00:39:29] And capitalism in a way that I don't think people really, really deep.

[00:39:35] **Jenica:** No, not at all. Um, it's actually the most common genetic disorder in the UK. Um, and one of the most in the world, um, I think next to kind of like cystic fibrosis. So like sickle cell affects a lot of people, more people than any other kind of genetic condition.

[00:39:54] But again, like you said, largely underfunded. Largely just not spoken about or not given the platform to share or to speak about. And then the thing is for myself and, you know, I'm just going to say this because this is just

like me and maybe the sickle cell community. I don't want you guys to be mad at me, but.

[00:40:17] 'cause I, I, I think a lot about, like I said, I, I don't know. I have this thing about thinking of others and things like that. So I know that where sickle cell sits, but then sometimes ranting about another condition. Like somebody else's disability or somebody else's chronic illness. I'm not necessarily feeling like it deserves any less attention than SQL cell does.

[00:40:41] Do you know what I mean? So it's not about taking away from something else to say, like, you know, well, this is worse than yours. It's just about also giving us that, that platform and that attention to say, Hey, this is just as bad or this also deserves just as much. Do you know what I mean? It's not a competition of who's worse and the who's is it's it's about.

[00:41:04] Shining the light on maybe those that need more attention or those that need it need it most. And I feel like, like politically there's, there's not enough being done like funding. It's sad when you look at the numbers compared to other conditions. Yeah. And also for me, and kind of, you know, we've secrets are largely affecting black people.

[00:41:29] It does affect white people, but then there's that whole. Sometimes, I feel like, you know, on one hand, where, where are the, where all the white people that have this condition, would you speak up more? Would that make a difference on the other hand? We always tend to have this thing about, you know, we need a white savior and then they come and save the day and then all the money and all the attention flows in.

[00:41:54] And I don't like that. There's so many different elements of, uh, yeah. It's a,

[00:42:10] **Suriya:** yeah, it just, it just, it just really kind of breaks my heart. When I hear more about like the medical racism that we experienced, the idea of like, you know, black people can take more pay and then obviously stick with solid. Largely is, well, it's not, it's not largely, but you ha you have crisis is also, excruciatingly painful based just kind of like.

[00:42:28] Oh, what does that mean when you go into the hospital and try and try and get support. And I just think that, um, that you said when you, when you realize it's not like a competition of like, oh, we, you know, is this against that? But I think it's really interesting too, when you on pick, hang on, why do I know so much about this?

[00:42:48] And I don't know about that. Or have the, I have these ideas about that, or where did that come from? Or what am I like, why am I thinking? And as somebody who is sick can experience like kind of a few different health conditions, it's really interesting experience in like one part of the hospital. And then you go to the other part of the hospital is, and I don't really think people really know about that political and economic side.

[00:43:16] How different aspects of health are focused on, which is, you know, it's, it's a, it's a really kind of a new thing that I've realized as I've got older. It's like, it's not like if you're sick, we're all having the, in an equal experience really there's inequalities. Even within the marginalized communities

[00:43:32] **Jenica:** at all.

[00:43:33] It's not, there's, there's, there's just no equality at all. And it's the same as I feel like sometimes. We forget, or we expect that in certain industries, everybody will be treated as equals. So, okay. It may be different in the workplace or it may be like this, but you know, the healthcare is a health care and everyone has to be treated the same and everyone has to be treated equal, but no, the, the inequalities in health care in terms of not only patient care, but also, um, you know, Funding, um, in terms of the wards and what that looks like, or how things are just down to the minute details of like, Decorations and pictures or the field of certain things.

[00:44:23] **Suriya:** I'm just saying like, what's finally talk about this. He goes, so how come you guys have got so many pictures and my

[00:44:31] **Jenica:** earnings

[00:44:32] **Suriya:** and this, and yeah. And like the way that people talk to you in certain areas is very, very different to you go over to other areas. It's like, oh, there's one little plastic chair and some sticky magazines.

[00:44:45] I mean, not anymore because of COVID. But do you know what I mean? Like,

[00:44:52] thank you so much for everything that you've shared today has been. So, um, Insightful and, uh, just beautiful reminders of things that Sickbabe need to hear. But everybody also, like you said, needs to remember that, like we, you know, we're, we're here and like try and reflect on the here and now. Um, So, yeah.

[00:45:13] Thank you so

[00:45:13] **Jenica:** much. Thank you so much for having me. It's been, it's been a pleasure and I can say hashtag Sickbabe,

[00:45:22] **Suriya:** it's always such a joy to speak to Janeka. I feel like she has such an energy of compassion and persevere. And I just think the work that she's done for the sickle cell community is incredible and really, really important.

[00:45:36] So you can follow Shenika on Instagram at just Jay Leah. And I'll link that in the description as well. And you can find out more about her book, my friend, Jen, which is a children's book. For young people with sickle cell, which I think is incredible. So please do follow more of her work. And yet it was such a great time.

[00:45:58] Speaking to her today

[00:46:03] Sickbabe was produced by, she wants a dog supported by contact data and arts council, England sound designed by the amazing Anyon Evans following. At Sickbabe pod for more information.

[00:46:30] Um,