

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] **Toni-Dee:** It's a colonial mindset. It's this idea that like, you know, if you're the most hardworking person, then you know, you'll get a little tree in the back. Um, which

[00:00:19] instead I'll give you a little bit of.

[00:00:25] **Suriya:** You can only the swap, the ableism for the racism. We can put some mysogeny.

[00:00:35] Oh yeah.

[00:00:36] **Toni-Dee:** That's

[00:00:40] wild.

[00:00:47] **Suriya:** Welcome to Sickbabe the podcast from my bed to yours. Hey, we'll be chatting about all the unspoken bits of being sick or chronically ill, everything from Ty and sex to Mary on Facebook, who thinks she knows more about your condition than Eugene. We hope that it can be a GC bedside chat for the no spoon days and just something to keep you company on days that you feel in.

[00:01:11] All right. And if you're not sick or disabled, don't worry. You can still have a listen, turns out capitalism, enablers, a miss for kindness all over. So I'm sure we'll have something to bond about.

[00:01:26] So something that I've been thinking about for the past couple of weeks is the idea of killing time. And I don't mean in the traditional sense, which for me is buying unnecessary, stationary and small little cute shirt. But for us, a sick people killing time potentially can represent the idea of reframing our relationship with pace.

[00:01:47] With time, with how much we can get done, what we should get done in a certain amount of time. And today I decided to invite Tony D to chat with me about this. Now, Tony DePaul is an artist and a producer, and she's currently working on a piece of art called dose, which investigates rest in progress, rest as resistance.

[00:02:09] And how do we as sick people live our life based on our body's clock and not on capitalism's clock.

[00:02:23] We're constantly bartering with our time in that way. Like, you're like, I'm not going to go to this party now, because then in two weeks I can go and support my partner to do XYZ. And it's like, you know, I don't know if people really get that. And like you can't w why you might say no to something, or you prioritize, what is.

[00:02:47] Quote unquote important. And I think that's also about time killing time. Isn't it? It's like different things become important as you are either supporting people who are sick or you're sick yourself because you're like actually in the grand scheme of things, I know for these people replying to this email right now is their level of importance.

[00:03:09] But for me, He's just had like a seizure or dizzy or whatever it might be. I need to lie down because what's the reality of what happens if I reply, it might just be the email. That means I ended up in hospital either. I mean, I'm, I don't think sometimes when you say things like that, people are like, people are like that can't be true, you know?

[00:03:38] And I think there's a denial because it's. Because it's almost unbelievable that that's the reality of it. And I think that's why people are like, they push back on it of being like, can you just quickly do this? And it's like, no, I can't because I have 0.5 spins left and I have to use that spoon. To get a glass of water in bed and get myself to sleep.

[00:04:00] So, um,

[00:04:02] **Toni-Dee:** I, I think I was probably still doing now a year and a half ago, if I'm honest. Yeah. I would say maybe. Yeah. Like, and actually it took. It took a really, really big dip in my mental health, um, and sort of suffering from quite a severe breakdown at universe a to start to. Maybe embrace the spoon system and to feel like that was a valid way of talking about where I was at with my energy, how I could or couldn't do something, but it's taken even, even from that, it was maybe another year and a half before I started being able to say that with confidence and to say that.

[00:04:58] Knowing say it with conviction and mean it and stick to it. Like one of the hard things about boundaries, right? It's like you, you, you put the boundary there. And then inevitably someone or something will come up to

push back against that. And for me, the hard bear wasn't necessarily putting the boundary in place.

[00:05:20] It was saying it and meaning it. And then, and then, um, sticking to it and being confident in saying. I told you I can't do that. So I'm not going to, um, and for that, not to feel unreasonable or harsh or like I'm lazy, but actually is sustaining me. Like that's what sustainability looks like. It's saying.

[00:05:48] I've said no, no thing. And not doing it like lock go in. Oh. But they sent the second email, so it must be important. So I'm going to have to do it like, or, you know, they've now gone from messaging me on Twitter to WhatsApp and then they've emailed me. And even though it says in my, um, you know, um, The foot of my email signature, that there may be a delay to email replies.

[00:06:17] You've still gone ahead and tried to contact me up to the platforms. Which it just infuriates me, but it's not an emergency, you know, no one, no one is going to die, but if

[00:06:34] **Suriya:** I might.

[00:06:51] I think it's also in the arts, it's a specific kind of experience as well as in it, because it's that thing of, because we have internalized this idea of scarcity in the arts as well about your opportunities in terms of. If you're not AST, you could be a starving artist. So how dare you turn down an opportunity?

[00:07:12] How dare you say no. So I think there's that thing of, so in sometimes I get that as well. I internalize it like, should I, maybe I should be rushing myself to reply to this email because if I don't then maybe I weren't getting money and all these kinds of things. And actually that feeds into, and also I think people have that are able to sometimes play on that as well.

[00:07:35] Because they're like, we, you know, we really want you to do it and we've got all this budget. And even sometimes I've got to the point now where I'm turning down things, which you've got a healthy budget, but I'm like, my body is literally saying no. And I think there's a whole conversation about capitalism and sickness and all how that weaves together and how we sustain ourselves financially.

[00:07:58] But it is also that thing of what about if we reframe it and put our. Bodily strength, our mind, strength and wellbeing, literally at the top. And then it just being like, my finances are fine. So then I'm fine.

[00:08:17] **Toni-Dee:** What are your priorities is the question that like should come before anything, right. And the answer isn't at the top, like wellbeing care, um, you know, access.

[00:08:30] If they're not at the top of the list, then we're actually not going to get anywhere because I'm still going to have to work against your able, as I'm still gonna have to exert those boundaries time and time again. I'm still gonna have to explain to you why I only am working. I'm only going to work three days a week for six weeks, rather than for two weeks intensively, 12 hour days, because it's not feasible.

[00:08:59] And I won't take time off. Like I will feel L um, you know, the sort of, even people who are marginalized. We'll continue to push back against that.

[00:09:15] **Suriya:** And then, um,

[00:09:17] **Toni-Dee:** yeah, I, it is really interesting cause I think, you know, if you, if you think that you've done a great job. Doing some thing. Um, I'm proud of you, but like who did you stump on to get hair?

[00:09:34] Just be mindful of who you're pushing out the way to, to get to where your rocks and like, okay. Yeah. You're a. A queer person. Who's like made all this space, doing whatever project, but like you haven't thought about the disabled people, the queer disabled people that you've erased from this conversation.

[00:09:55] You haven't thought about those, those people who needed access to your event to even make it there. Do you know what I mean? And you're patting yourself on the back because everyone's everyone showed up and showed out, but there's like a bunch of people home does not include. No, I'm not seeing in your vision are not a priority because you know, well, you know, I've got my community here.

[00:10:20] Yeah. But it's missing, it's missing a bunch of people, isn't it. But, you know, even in your sidelines, who is in your sight lines, you, you looking out for, and I feel like. You know, if your priorities are care and wellbeing and access, then like some of the most marginalized people will end up in your sight lines because you're looking out for them rather than like they saw of patting ourselves on the backs, because we did the band minimum, like even like black protest protest them.

[00:10:56] Roots that like have stairs on them and like, uh, in places that are not wheelchair friendly, it's like RA you look really out here on the streets protesting for whatever reason. And again, Sightlines, you've just not thought about. It's part of your vision is part of your, the broader thinking for you.

[00:11:18] Like you, in fact, it's not broader thing, Ken it's like the band minimum minimum,

[00:11:26] **Suriya:** and by the set one and then gone, you know what, I forget the rest. I would just think about step one and sorry, 30 D just got some sort of flight. It's quite varied.

[00:11:37] **Toni-Dee:** Yeah. I've got a window open and it's high my room and clear.

[00:11:42] The funny

[00:11:42] **Suriya:** thing is nowadays, it's not, it's not, we're not friends, please.

[00:11:54] Please

[00:12:01] at this point, we couldn't remember how to pronounce Leah's name. The. CareWork dreaming disability justice. So we wanted to make sure that we, um, pronounced it properly. Um, their name is Leah Lakshmi, perhaps now Sarah Mann singer, and they write the book care, work, dreaming, disability, justice. Um, so in care work they say about how, how disabled people are angry.

[00:12:29] A lot of the time I'm frustrated. And it's like, I think that potentially. Is off-putting to people, quote unquote. And it's like, yeah, I'm angry. My head hurts. My legs are aching and I'm busy.

[00:12:44] **Toni-Dee:** So we're in pain all the time.

[00:12:47] **Suriya:** Be a little bit irritable. Let's be real. We're all a bit irritable when we're not feeling well.

[00:12:54] And then on top of that, people are telling you that you're lying or it's not really real. Um, but it is interesting in the sense. The palatable sick person, isn't it. It's like you're able to either be, I think she talks about the hero sick person who is the inspiration and overcoming adversity despite their sickness, or you're really sick enough that people can pick up.

[00:13:18] And put you into this box, the in-between space where we exist, where we're like, just fix up and make sure that I can access this space. And yes, I'm angry because I've got a migraine and no, I'm not inspirational because all I'm doing is writing emails and doing my bad. There's not many spaces for that.

[00:13:38] And I think people find it hard to process us because it's only, I, for example, habit, I'm having to reframe our relationship with time because I was, I grew up as an overachieving kid, like a gifted and talented kid. So I was able to do a lot in a short space of time. And I used to kind of frame in my validation and identity around.

[00:14:01] Well, Sariah look how much you did. Wow. Wow. Look how much you did. And now it's like, when I'm caring for myself and actually my sick friends are like, yeah, like we're in the background, gasoline children, because we had a nap. We're like, yes, take a nap. Woo.

[00:14:22] But obviously the capitalist world based on its validation, doesn't um, Pick you up in that way, or how are you as an inspiration unless you're overcoming your pain. And that's the thing that I'm interested in in terms of time? How do I sit with that? You know, the fact is I feel really proud of myself and great because I've worked two days this week when actually that's all and that's all I could do.

[00:14:53] And the rest of the time I spent. Looking after my body preventing it from going into a bigger flare up or these kinds of things, but no one sees that. And it is in a, in a human way is honest to be like, it's a weird feeling of having this thing that you're not humanly getting validated for in that in the same way.

[00:15:15] So that's also the part of reframing it with time is like, you want to be like, yeah, I didn't, I haven't got any more commissions in the last month, but you know what I did do, I Le I researched that really great cream for my aching legs. And actually I've been using it consistently for the last two weeks.

[00:15:33] And I'm actually really proud of the fact that I didn't forget it.

[00:15:38] I guess we just have to text our sick friends about that. Isn't it.

[00:15:44] **Toni-Dee:** I remember talking to my friend and sort of collaborate on various things, I guess, um, and McGarrity about how the, um, uh, queer milestone is different than ASIS hat milestone, because we construct our lives, um, away from what is considered normative. So, um, you know, We are, we are celebrating things in different ways.

[00:16:13] Um, and we have learned to, to embrace that and to feel good about. Not doing things the way that society has told us that we have to do things. Um, and I think disabled folks do that in like so many wonderful ways, like affirming each other on those, um, that they're not even milestones, it's like affirming each other because the world will tell you that you're not valuable and like affirming each other because outside of being.

[00:16:50] There is value in being in living outside of gifted and talented and the world, won't tell you that that's the case, or like, you know, there's, um, there's this like very strange, um, uh, No shit, especially in the black community that like, you will work yourself out of oppression. Like, you know, your class too, which is just like, it's just capitalism manifested

[00:17:26] **Suriya:** you say it like that.

[00:17:27] It's like, you hear the ridiculous, like, yes, you know, we're going to work then

[00:17:33] **Toni-Dee:** money. You just won't be oppressed anymore.

[00:17:37] **Suriya:** And experiencing racism.

[00:17:43] **Toni-Dee:** If I'm wealthy, then racism,

[00:17:49] a colonial mindset. It's this idea that, you know, if you're the most hardworking person, then you know, you'll get a little tree pat on the back, which

[00:18:01] **Suriya:** know racism.

[00:18:08] **Toni-Dee:** But instead, I'll give you a little bit of ableism.

[00:18:14] **Suriya:** You can either swap the ism for the racism. We can put some Misashi.

[00:18:25] **Toni-Dee:** That's hopping more, say wild. Yeah. It feels like there's this sort of like aspirational, um, day that, you know, if you're you're working hard enough, then things will get better. Get I'm doing like that. The act quotes get better. Um, In the meantime, we are going to, um, belittle anyone that doesn't overwork.

[00:18:54] We are going to shame folks who have benefits class. We are going to make disabled folks feel like if they just worked a little harder or were a little less sick all the time that maybe they too could stop experiencing the bad things that are happening to them. Um, And then the, the irony of like what you're going to work out your oppression, right.

[00:19:17] You're going to like, what are you gonna work out at marginalization right now?

[00:19:24] **Suriya:** What you're doing right now is this great. Certainly is like the big shoulders. You're listening to the side of oppression. This is it.

[00:19:37] **Toni-Dee:** And it's like, they literally are power walking out of

[00:19:42] **Suriya:** power, walking out of oppression that needs to be on the tee. T-shirt.

[00:19:54] I think there are so many ways that we hold our body so many ways that we hold our buddy and expectations. In words that have been said to us about what it means to live in this world as a sick person, what value do we bring, where we're not just chatting ourselves on a cog and rest disrupts all of that.

[00:20:13] Rest says you are a person wholeness who deserves kindness, love, compassion in everything that you do. And if you stop nothing else is going to fall apart. You will always be able to get back to it tomorrow. So please take some time for yourself for the rest of the day to just breathe and rest and take.

[00:20:36] Even if it's five minutes for yourself.

[00:20:45] You can keep in touch with Sickbabe at Sickbabe pod on Instagram and Twitter and see all the amazing stuff that we've got coming up for you. This podcast was produced by. She wants a dog. You can follow them on Twitter at she wants a dog. See you next time.