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[00:00:00] **Suriya:** Oh, you've seen my funny more times than

[00:00:08] everybody else. Didn't know where to do.

[00:00:17] 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 tired sex to Mary on Facebook who thinks she knows more about your condition than you do.

[00:00:36] 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.

[00:00:53] All right. Let's get. Hey Sickbabe. So I'm really excited to share this conversation with you today. I spoke to Sasha and, um, her pronouns are she and her. She has set up the womb room, which is an organization that aims to kind of educate people with wounds and uteruses. How can they feel more confident in knowing more about their body to advocate for themselves in the health environment, but also to kind of undo some of the shame that we know has, um, come over time, they've living in a patriarchal society, which teaches us that we need to be ashamed of certain genitalia and not advocate for ourselves.

[00:01:33] So as a bit of a content audit, we do talk about vaginas, vulvas sex, and go into a little bit of detail at times about, um, different things that can happen with your body. So if you don't want to listen to those bits, please feel free to scroll forward. And, um, I hope that you enjoy the rest of the conversation

[00:01:55] **Saschan:** when you have a chronic illness, obviously at that point, I didn't have a chronic illness. But you're very conscious of, oh, I'm using up a lot of services sometimes, and then you feel bad for accessing them. And I felt bad cause I was going to Amy so much and I was like, this is not a good use of, of NHS resources. Um, and so in

[00:02:14] **Suriya:** the end, even at that point, you wanted to start striking. Excuse me, I'm in excruciating pain, but also just want to do evaluation of the resources. And I really don't think this is a good use of it. Okay. Anyway, do my scan basically.

[00:02:26] **Saschan:** Cause I was like the amount of times I was keeping a record of how many times I was going to any, I was like the amount of times that I've been here, there's no way that this is the most effective way to handle what I'm going through.

[00:02:38] And so in the end, I went to a hospital in Birmingham, which we shot on him. And I saw a consultant there. And, um, when I went into a and E the consultant who was in charge of the gynecology department that night, so that wasn't her problem. She didn't want to see me. I was already scheduled to have surgery in Liverpool, so I should go back there and see them.

[00:03:04] I shouldn't waste her. And the only reason she agreed to see me was because the junior doctor who was in the AME doing triage, said, if we send her home and she dies, I'm not having it on my conscience, that we didn't do everything that we could to help her. And that was the first time that anybody had said to me, oh, by the way, your condition is.

[00:03:25] Bad or so serious that it could cost you your life. If we don't do something about it imminently and up until then, I just thought, okay, it's a fluid-filled cyst. Nobody had really explained the dangers associated with a cyst of that size and the symptoms I was having. So the consultant did see me, but she only agreed to see me one because the duty doctor told her and to.

[00:03:51] Under the, she said that she received me. If I allowed her to perform an internal examination, even though I had all this paperwork for all of my visits and internal examination would not tell you anything new. So I said, yes, because I thought if I say, yes, she's promised that she'll treat me, she'll help me.

[00:04:15] If I say yes to this. So. I said, okay, we're going to do the internal examination. Then she brought in this junior doctor, another junior doctor, um, from somewhere and was like, so this doctor's just going to sin. Hope that's okay. You know, if you want to be seen and treated, then, um, I'm going to perform the examination and then I'm going to let her do an examination

[00:04:38] **Suriya:** as well.

[00:04:39] Gosh, this is, it's always the stages of. You're just handling. You're constantly handing over your body. Aren't you even kind of, if you want this support giveaway your agency, that's the only way that you can do it.

[00:04:54] **Saschan:** When I came out of hospital, um, I think I just didn't really, there was no support. I was having a bit of an identity crisis.

[00:05:00] I was like, questioning, what does womanhood mean? Who's going to love me. I never wanted to have children, but then I was like, oh my gosh, I do want to have children. And then it became this obsession in my mind. And it was just, there was just loads of things that are really difficult to cope with. And so.

[00:05:17] My mom was like, oh, you keep complaining that nothing exists. There's no support services. So why don't you just create one? So then I started blogging about what I was experiencing and a lot of my blogs were really humorous and I think that's why people, part of the reason people enjoyed them and the women started getting traction because it wasn't all just like doom and gloom.

[00:05:37] It was me kind of reflecting about in a humorous way about all the things that you're going through, particularly. No, none of my friends could relate well at 19 everyone's out like drinking at like freshers parties and bar crawls. And I'm just like here at the hospital

[00:05:53] **Suriya:** at three o'clock in the morning, most of the

[00:05:55] **Saschan:** time we just had very different existence.

[00:05:59] So it was. I started the wind room blogging as a way of kind of like coping with it was very cathartic, like coping with what I was experiencing and how I felt my identity was changing. And then it kind of just blossomed from there. It's been nine long years. I can't believe it's actually been that long, but

[00:06:20] **Suriya:** amazing.

[00:06:20] And I think what I love about it is, like you said, in terms of you were 19, you have no idea what this thing was and you had no information on it. The word, Mari is a great way to make it accessible for young people, especially because, you know, I think there's also a thing within hospitals and doctors of them having this myth that young people never get ill, or like, we've like, I'm like, where is that potion?

[00:06:45] That every young person's mentor drunk, because I did not get a Microsoft. And did a while ago, because as a child, as a young person, I would go to the rosters and I think it's this. And they're like, oh, that could never be true. Like, you don't get that until X, Y Zed, and actually young people now being empowered.

[00:07:03] The kind of information that you share means that they can fight for that, especially. If you've got a of, it's like, there's a lot of misinformation. And often people don't know about things like PMDD and even only now where people talking more about fibroids and endometriosis. And so often people are like passed away, but not passed away, like passed off with like information that's.

[00:07:30] You know, not, not factual and they have to live with all this pain. So I think, yeah, basically what you're doing. Yeah. It's really valuable. And I think also, I think what I wanted to talk about a little bit with you is actually something that's inspired by TikTok. I mean, TikTok is literally my life right now.

[00:07:49] I only take talks all the time, like saying I'm going to bed at 10:00 PM and staying up till 2:00 AM watching TikTok. Yeah. It's not healthy, but yeah. What is right now, like literally we're just coping. And one of the textbooks that I saw actually was a young person talking about vaginal discharge. And I actually find it really inspiring because I think this person was about, um, I think they were probably about 1819, and they would just kind of breaking down the myths about vaginal discharge for other young people to hear and, um, and be like, this is normal.

[00:08:20] This is what it might look like at this time in the month. And those kinds of things. And it really made me think about, for me, I feel like I'm quite an open person about my body or I don't try and. Not ashamed in about things. Um, and I think once you've gone through the hospital a few times, your relationship with what quote, unquote, dignity changes completely, doesn't it?

[00:08:42] Do you know what I mean?

[00:08:47] So what, what is your journey, I guess, would shame or things that you try and do to undo shame like in your body or just any experiences you've had around. Ooh,

[00:08:59] **Saschan:** that is a good question. Um, I think in a lot of ways, I feel like I'm very fortunate because my mom worked in, um, sexual reproductive health for a very long time.

[00:09:13] She set up, uh, one of the first mother and baby projects for women who were HIV positive in the country. And so. Discussions about your body or sex or relationships were never to boot in my house. There was never anything that was off the table. And so also my Nan very shameless woman

[00:09:39] does not know shame. So I think because

[00:09:44] **Suriya:** we need to see what's your

[00:09:47] **Saschan:** heritage. So my dad's parents are Jamaican. Um, and my mom's dad is Jamaican, but my grandma is white, British. Okay. And, um, yeah, she does not know she does. Uh, she doesn't know shame. She never knew shame. Uh, when I was growing up, my grandma, she just had no filter, no filter, even up until like, when.

[00:10:13] She was. Okay. I'll tell you a little story. So one time my mom's friends set up a laundry company. And she had like a night at her house, you know, you have like an enzyme as part you, so it was kind of like that. So she had this like laundry pile up her house and for the launch and my Nan was there. And when I'm put on this, like little, it was like ho cutout with like a fur and feathers around it, like bra.

[00:10:39] And because that, and she was just like parading around the house. Um, At this point, she was probably in her late forties. She must've been in her, maybe even her early fifties. Right. And, uh, she just parade around the house and then she puts on those, you know, there's like 1930s classic films, and they've got these long silk robes with all the, for around the

[00:11:03] **Suriya:** corner.

[00:11:04] **Saschan:** And she puts that on top and it's like bright red. She was like, oh, I wonder if the neighbors want to show because she goes outside on the street and it gets all my cousins, scooter and socks.

[00:11:24] **Suriya:** And she

[00:11:24] **Saschan:** did not care at all. She thought it was hilarious. Everyone else was

[00:11:29] **Suriya:** amazing. She just,

[00:11:31] **Saschan:** she was just, the shame did not exist. Shame did not even up until when she was in hospital and she was dying at. Okay. Like you lose your dignity because you know, somebody had to clean her and take care of her.

[00:11:43] And, um, she'd always been very independent. And so they had a male nurse. And one day we were there and she just like had a wash and we'd just come. And she turned around and she was like, oh, you've seen my funny more times than

[00:11:59] **Suriya:** what

[00:12:05] everybody else did. I

[00:12:06] **Saschan:** know where to look, but I was just like, that's very typical of my dad. Just no shame. Just say whatever

[00:12:11] **Suriya:** comes to mind, sex positive, man. I didn't see the kind of role model. Sounds like really shaped you a hundred percent.

[00:12:22] **Saschan:** And so I think I just don't, I don't really have much, I don't really feel shame about my body as I think that was really helpful when I was going through the experience when I was first in hospital and then even the experiences I had, you know, not having to have my diagnosis of endometriosis and fibroids and politics and everything else.

[00:12:43] Um, I just didn't really feel ashamed or. My body, but I also think it's a process of unlearning and relearning the relationship that you have with yourself, because my body fluctuates quite a lot. So since my first surgery, I've really struggled with water retention. My weight can fluctuate quite a lot, and that can impact how I feel about myself, but then I never feel.

[00:13:08] I never feel ashamed of how I look. I might not always feel comfortable in my body, but I don't ever feel ashamed of my body regardless of how it looks or what is happening at any given time. And I think for me, it's, it's a conscious decision to be kind to myself and to not apply additional outside pressure.

[00:13:30] To how I'm already feeling, because I know that I'm already struggling with things and it's not going to make me feel better about myself. If I sit here, like picking myself apart. But I think it's one of those things that it's a

lot easier said than done. And I truly truly believe that it's because there's not a culture of shame that I grew up with, like from my mom and my Nan and my aunts, I think.

[00:13:56] I'm just not really, it doesn't really bother me as much.

[00:14:00] **Suriya:** It doesn't go to you. That's amazing. And also the power of what other women can do for us. If we have that kind of representation in our lives or, or also the impact of those little comments that might be made of like, I don't know, just about cleanliness a lot.

[00:14:16] I think with people who have like pubes and discharge and all these different things, it's, it's often related closely to. Being clean, which I think maybe people have, um, fear around. Um, so what would you say is, I guess, as someone who maybe doesn't have it, didn't have the kind of upbringing that you had, or even those little, those little comments that people might make about their body.

[00:14:44] Um, do you have any advice about like, how do you overcome? Cause obviously I feel like when we were growing up, we had that whole thing that went through about like labor, labor, pasties. And I mean, I feel like we're kind of coming out of it more where people are talking more about this lots of, you know, lots of different ways that layby or vaginas can look.

[00:15:02] But I feel like that was a big thing when I was, I just remember it a lot that I remember watching this documentary when I was like 15 and thinking, wow, Is this something that we need to be worried about now? I never thought that we needed to be worried about. Um, yeah. So is there anything that you would say to, um,

[00:15:23] **Saschan:** I think it's a difficult one.

[00:15:25] I think you have to, first of all, it's understanding if there's something you're experiencing or a particular way that you feel about your body and. You recognize that there is a feeling of shame or there is a behavior or a pattern that you exhibit, which is steeped in shame that you feel about your body or something that's happening to you is unpacking.

[00:15:49] What is the root cause of that? Like where do, where do you feel like that originated from in your life? And I like, so I go to therapy. I recommend therapy for, um, but also therapy is not always accessible to everybody. Um, but one of the things, obviously a lot of the time we talk about in therapy is things

that happening in your childhood, that then impact how you respond to things or engage with things as an adult.

[00:16:16] And so I think if you, if you recognize. Shame for you is steeped in things that were taught to you or things you experienced as a child. It's sometimes it can be reevaluate in the relationships that you have with the people that taught you to feel that way about yourself. Sometimes it's, it depends on whether you also, if it's like matriarchs in your family, for example, do you have the kind of family dynamic?

[00:16:42] That's a conversation you could have with them about, you know, I've been reflecting on XYZ ed and I kind of feel as though certain things that happened when I was younger or things that you might have said had this impact on me, because some people do have the kind of family dynamic where they can have that conversation and people will be receptive to that.

[00:17:00] But some people don't. So I feel as though if you don't, it's also understanding. You have the autonomy and the power to remove yourself from any room where somebody makes you feel uncomfortable about yourself and recognizing your own power is something which is a process, which I think takes a lot of practice because I feel that we're not really socialized to.

[00:17:27] Be assertive in the same way that men are typically socialized to be assertive or very dominant, or just ask for what they want or be very open when they're upset about something or they don't like something that you've done. I don't really think that we're socialized in the same way to use our voice in the same way to tell people when they do something that makes us feel uncomfortable.

[00:17:54] And so I think it's, as you're starting to get older, recognizing that you have the power and the autonomy to do that and taking the steps and also not feeling bad, if you don't reinforce that, that your boundary with somebody is that you don't appreciate being spoken to in that way, or you don't appreciate that comment.

[00:18:11] And that could be from anybody because sometimes the comments that make you feel ashamed will come from your doctor. They're not always people who are in your family. They're not always your friends. Sometimes it's other professionals that you see when you're seeking help. So I think it's, for me, it's a process of not allowing other people to shame you and then unpacking where your shame comes from originally and trying to work on that.

[00:18:38] And I think as well, it's really important to find, find other people that you connect with. Who are in positive influence in your life. And that can be people that you find online. It could be literally through podcasts that you listen to, like exposing yourself to new things that help you deal with how you feel about the things that you feel ashamed about and why, and connecting with people who can positively reinforced like new habits or new behaviors or new ways of thinking and new practices in your life is really, really powerful.

[00:19:12] **Suriya:** Yeah, really powerful. I think actually the, the amount of, um, influence that just having, having people talk about things. Without that error of embarrassment or whispering, oh yeah. The vagina,

[00:19:35] this kind of culture of not talking about bodies in that way means that actually it feeds into how we relate to ourselves when we are unwell as well. Because I think it's like, there's so many people who are having really painful periods or they're having, you know, they're putting on unexplained way and they.

[00:19:56] And then they, they're kind of in a way gaslighting themselves something. And I shouldn't be worried about this. I shouldn't be worried about that or not going to the doctors to have it because they, they, they imagined this catastrophe of what it's going to be like when they have to, you know, show parts of their body.

[00:20:11] And obviously we have it with the whole cervical cancer screening that so many people don't go because there's like, I've heard people say they're not going because they. They haven't shaved. And so they have to wait until they've shaved until they can go to the doctor to have these things. So it's like, whoa, like it's actually affecting our house in that.

[00:20:29] Um, as well. So having that D shaming ourselves around our body is really, really important and has such a, a long lasting impact in so many ways. And I feel like, um, everyone should go and follow. Is it at the wound room on Instagram? Yeah. Yeah. Right. So, yeah, so, and I think having information, like what you shared really helped me be able to advocate for myself in a way that I wouldn't have, if, if I didn't have that info, I think surrounding ourselves with more information like that, with people who don't, who talk about it confidently.

[00:20:59] Really helps us in more ways than we know. Um, I was in a meeting the other day and somebody, you know, quite, quite, um, casually and confidently said, oh yeah, my herpes are playing up. Cause I'm really stressed. Um, they would call in about, um, herpes on the models. But I think even

saying the word herpes and for people who have genital herpes, it's like a thing, you know, it's such a stigma and the shame around that, that I think the more that people just talk about it it's it's it helps.

[00:21:28] Definitely.

[00:21:30] **Saschan:** Definitely I think as well, like to go back to something else that you were saying, I think we really underestimate how the culture that we have around diet and around body modification and around. The conversation and the narrative around your body should look a particular way. Um, and even who that is, who that is for, is it for you?

[00:21:59] Is it for other people in society? Is it for your partner? Is we don't understand. We don't always opening recognize the knock-on effect that that then has on. How you manage other aspects of your health?

[00:22:14] **Suriya:** Also, again, it's like all these intersections, capitalism access to resources. If I only have my saline to clean my face, then that's all I'm going to green my face all these years.

[00:22:29] I know I'm going to get loads of people being like, don't greet me face with Vaseline, but what I'm trying to say is the fact that. You know, we, don't not, everybody has the same access to resources, do they? And, and especially a particular bodies are put under more pressure to groom and change and all these different things.

[00:22:53] You have any practical tips about having sex when you've got in endometriosis? Uh,

[00:23:00] **Saschan:** practical tip. Um, I think sometimes it can be difficult when you have end dates, track your periods. So I always recommend people track their periods cause it helps you also track your symptoms. So you start to notice patterns in your body over time.

[00:23:14] Um, I track my cycle, but at the moment I recently had a diagnosis of subclinical hypothyroidism and. My consultant said, like I'm not ovulating. So I'm has been having a period every two weeks. And I was like, oh, that's kind of weird. Why is that happening? And it's because I'm not ovulating, so I'm not getting enough progesterone.

[00:23:36] It's not keeping the line of my women tact. Um, So that also makes like sex really difficult because I don't know how long I'm going to bleed for

what the bleeding is going to be like, will it be heavy? Will it be light? Um, but I think if you're conscious or you're aware of like what typically works for your body, what's going on with your body, that's a good starting point because.

[00:23:55] You will know how best to prepare if you're having sex. You also don't always want to be like having to do deep preparation. Sometimes it's the spontaneity is the fun of it. It's not every day. Let me make a note in my diary Friday at six o'clock. But, um, I think things that you said, like making sure that if you know that bleeding is something that could happen for you, like having clean sheets ready or having a towel or, um, Having things like I swear by magnesium spray.

[00:24:28] I love it is absolutely fantastic. Or you just spray it on your pelvic area or even on your joints. If you've got like joint pain and it really helps that if you're having discomfort, it works almost instantaneously. Um, and you can get like magnesium oil as well that you can kind of like rub it in. So if you do start having discomfort, even like things like her, some ibuprofen.

[00:24:51] Yeah,

[00:24:52] **Suriya:** I'm imagining like this and that, like, I feel like we need to make like some sort of romantic scene where for like, you know, people with pain and you'd like get out of the magnesium oil and put on some candles. And my Sergeant, I mean, why not me?

[00:25:07] **Saschan:** These are all things that will make your experience more pleasurable and enjoyable and also serve very practical.

[00:25:13] Uh, practical purposes as well for your life, cause they'll help make you more comfortable physically. I think that's really important. I think also. Understanding, like you said, like, what are the positions that work best for you? Because some things are going to be really uncomfortable or really painful, depending on like your partner, the position that you're in, um, how long your cervix is.

[00:25:39] So typical cervix is about four or five inches. So it, depending on whether you're using like toys or whatever, it might be, it could be really uncomfortable in certain positions if they're very like deep penetrating positions. So doing things, finding out over time, the things that work best for your body and prioritizing those.

[00:25:59] Cause I think as well, sometimes when you're having sex, you're so conscious about what your body is doing and how you look. That you're not actually present in the moment, so you're not really enjoying it. It's it can be come very performative, particularly if you have a chronic illness. And so I think it's really important to like take a step back from yourself, make us all feel as comfortable as possible and work out what works for your body and also to be really confident in communicating what works for your body, for your partner, because anybody who really cares about you and has your best interests at heart.

[00:26:35] It's going to take that into consideration and they will consciously and proactively do the things which bring you pleasure because it's a process of give and take and it has to be mutually beneficial. So communicating your needs. And that doesn't always have to be verbally. It could be in whatever way you feel comfortable with.

[00:26:54] Some people would prefer to like, write it down in a letter or a text or a WhatsApp message or whatever. So working out what method of communication works best for you to communicate what you like or what you don't like. And also not being afraid to say, like, if you're in pain or you're in discomfort in the moment just saying like, I think I need a minute to like stop.

[00:27:12] I think sometimes we worry about, oh my gosh, she's going to kill me if I say that. But it's like alternative. Be in like saving pain for the next three days.

[00:27:22] **Suriya:** This is it. Isn't it? I think I saw this like me once, where it was like all these different types of sex, these things that happen in sex that we don't see in like porn representation, where it's like, when you have to take a break or someone gets thirsty or like, you know what I mean?

[00:27:34] Or you go in, I don't know, there's lots of you fall off the bed, just all these silly things that can happen in sex that we don't see the representation of. And I think, and people with chronic illnesses, it's like. We've internalized the idea of like, oh, I'm being difficult and not doing it. Like the movies.

[00:27:51] Cause I've got a cell or whatever. And like you said, also paying for us might mean something like very different than just the usual pain that people by getting get insects, which it might be like, oh, it's a little bit of discomfort, but it could mean that like it's exacerbating something or, or, or et cetera.

[00:28:08] So listening to your body. Is really important. And also when you were talking about, you know, exploring different positions that work for you, that's like kind of exciting for, you know, I think we do. We sit, we think about all the, sometimes negative things, quote unquote that come with having any illness, but how amazing is it to be like, actually I need to explore these different.

[00:28:31] Yeah. So it's part of actually making it spicy in the bedroom. We've got to explore these different things. So yeah, it's actually a benefit dating someone like me. I think that that's, that's what I think. This person. Yeah, exactly. This person can go with. And our bodies, like, you know, bodies are quote unquote gross on there in loads of different ways.

[00:28:53] And I think it's, again, undoing the myth that we've got this perfect pristine body that smells like, you know, linen and clouds or whatever it is. And actually there's loads of different things that come about out of your body and your body makes loads of different noises. And I think. When we think about it like that, this is just one of the other things that some people's bodies do.

[00:29:20] Thank you so much for chatting with me today. I really enjoyed our conversation. Um, pardon me? Yeah, thanks really great. It's making me really, it's making me feel really like inspired and empowered about bodies and just even talking about it with you in this way open way. It's really, really amazing. Yeah, that was great.

[00:29:39] I think when we think about health care, It's important to remember that so much of it is not created equal and a lot of things that are influenced by patriarchy and misogyny and lots of these systems of oppression. I mean that it has a direct impact on how we relate to our bodies and the shame that we carry.

[00:29:59] So in areas of our bodies because of how society has taught us that we need to relate to them. And so I really love the work. That session is doing that the womb room, because it is challenging all of those stigmas and the shame. And just even in conversation with each other, it's important that we can say these things and be open and, and encourage that.

[00:30:18] To question why we think certain things about certain aspects of health. Um, so if you want to find out more about sessions work, please check the link in the description that we've put at the womb room. And I really hope that you enjoyed this conversation today. As much as I did, Sigrid was produced by, she wants a dog supported by contact data and arts council, England sound designed by the amazing Anyon Evans.

[00:30:43] Follow us on Instagram at Sickbabe pod. For more information.