

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] **Pippa:** You mean the cancer glamor?

[00:00:02] **Suriya:** I didn't want to say the constant level, but I did was thinking about it, know, um,

[00:00:10] Welcome to Sickbabe, the podcast from my bed to yours. Hey, we'll be chatting about all the unspoken bits of being sick, chronically ill, disabled, whatever words you choose. Everything from tide sex to Mary on Facebook. You think she knows more about your condition than you do. We hope that it can be a GC bedside chat for those low energy days or just something to keep me company on days you feel.

[00:00:40] And if you're not sick or disabled, don't worry. You can still have a listen, turns out capitalism and ableism is screwing us all over. So I'm sure we'll have something to bond about.

[00:00:54] So this is a really special episode for me. I get to chat to Pippa who is my really good friend and also the producer of this podcast. So I think it's really. Um, such a pleasure to be able to share this moment with her as we've gone on such a journey to develop to where we are now. And, um, me and Pippa just talked generally about what it means to be a Sickbabe.

[00:01:16] What are all the inequalities that go within that? All the, sometimes the challenges and the traumas that come from someone who repeatedly has to go into hospital has multiple different complexities. And in our conversation, we kind of share a lot of thoughts and ideas about how we feel about. The systems that are, are the healthcare or the campaigning.

[00:01:37] And just as always with every episode of our podcast, these are our thoughts and opinions and sharing our experiences really. And shouldn't be taken as a. Advice or as a foregone conclusion about anything, we are just people sharing and connecting with our experiences. So I hope that you take something from this podcast episode today.

[00:02:01] Um, so Pippa is an independent producer. She's an amazing friend. Um, she's done some really brilliant work within the art scene about inclusivity and just really bring in some amazing artists stories to stage and to life. Um, I'm really, really, um, I feel privileged to have been able to chat with her today.

[00:02:22] **Pippa:** Words are a lot. Right. Um, which is tricky because no one can see like the weird faces that I'm playing when I'm going. Ah, don't know what words to use, because I think that, um, I think that language is really loaded, uh, and particularly. In this bit of the conversation. So how we talk about sickness and illness and disability, um, and what words we can use and what works we can't and what validates us.

[00:02:50] Um, what's feasible. What's not what the barriers, uh, it's all stuff that I think I'm really, really still working through. Um,

[00:03:01] **Suriya:** What do you, what do you, what, what words do you feel like you fall on the most? Like, for me, I love using Sickbabe because it is, I feel like it's a bit cheeky, which is a bit mean.

[00:03:11] And, um, it feels weird when I say to people that I'm celebrating, being sick. There's something about sick for me. That is.

[00:03:25] Sexier mice. I was

[00:03:27] going

[00:03:27] **Pippa:** to say there's something about Sickbabe as a term that feels kind of glamorous that I quite like. Yeah. I'm a bit, um, Sickbabe um, well he does it because depending on like how you put the inclination, right? I'm sick, babe. There's loads of different ways you could like express it.

[00:03:48] That could change it. Meaning, one of the things that, um, I guess I really, really appreciate about our friendship is that you, uh, encourage me in that direction on a really regular basis. And sometimes that's like a stupid meme. You send me. And sometimes that's an Instagram account that actually potentially as quite life-changing for me to go follow.

[00:04:12] Um, but I think. That like comfortableness and ownership without, I'm not, I'm not as far down the path as I want to be, but I think, I think that's normal, right? Like I think it's okay if you, I think I talk a lot about cycles of grief and acceptance, and I feel like that's where I've been for eight years now where I'm probably going to be forever.

[00:04:41] Like yeah. Grieving for the things that I used to have and I used to be able to do and accepting what I have now and what I'm now able to do. Um, and so yeah, that, that cycle, and I think that's, it's interesting that that's so

visceral to me because I think that, um, because when I got sick, uh, it happened at a period of time when both my parents died as well.

[00:05:08] So it was all tied up with this. Very literal, um, traditional, um, sense of grief as well, like a traditional sense of grieving. So, so somehow they're all sort of intrinsically linked, but the words I use. The most is probably sick and ill, probably sick more than hour, which I know I've learnt very recently in working in contexts that that word is more loaded for some people than ill.

[00:05:43] Interestingly, um, still haven't quite done all the research to understand that having. Not quite there with all the reading that I needs to do to understand some of that, the detail of that particular tension. Um, but they're interested in is

[00:05:59] **Suriya:** come on gone. Yeah, it's just interesting. Isn't it? In terms of, we're discovering a little bit, the experience of becoming sick disabled in, um, so I was diagnosed when I was 17 with a Brain condition, which has led me to.

[00:06:19] Uh, life of varying disabilities. Um, but I know that that is it's you learn more about what it means to be part of the disabled community for those who have had experiences from birth or those who have become disabled as a result of an accident. And there's so many different nuances and intersections that fall within.

[00:06:40] This community and this wider wide spreading to it. And I think that the real amazing positive is that those people who weren't able to voice the barriers that they face in society before we're able now to talk about it, but it also uncovers this other layer of complexity where before we were like, oh, I think it's like, basically it's like any group of marginalized people, isn't it.

[00:07:04] There is never homogenous. And it's, it's always intersectional.

[00:07:08] **Pippa:** It's totally what I was about to say. It's, it's the complexities of grouping people together, but also, um, the benefits of that are really high. And actually like, if you not to get all like crazy political, but like if you pan out, like you see that in relation to collective action and identity politics in a kind of much broader sense, like the tension between the two things like, and so.

[00:07:34] I often do now use the word disabled. It took me quite a long time to feel like I could go anywhere near that word. Um, but through many, many conversations with many different people, um, who identified within the second

stable communities, don't even know if that's okay, like sick and disabled community.

[00:07:54] I'm not sure, you know, I potentially have just really offended many people with that little phrase there, but like, um, Yeah, I was, it took me a long time to use that word and I will still use it as a shorthand and it can be useful in certain contexts. Um, but I wonder. I wa like, I, I think it's really interesting the value of bringing people together for solidarity and collective action, but also the need to have individual identities within that and how, how those two tensions can sit alongside each other to create positive change with.

[00:08:34] Um, minimizing or neutralizing specific and particular different experiences that have crossovers, I guess, of, of barriers or crossovers of feelings or crossovers of ways to resolve them, to help them. Um, gosh, I've just gone on a massive ramble and I can't even really

[00:08:57] **Suriya:** know. Everything that you've said is really, really valuable.

[00:09:01] I like you, I think when you get into your flow, sometimes those are the things, when we say the most profound things, anyway, that's all good. Yeah. So drift pick it up from what you said about like the different, extra nuance experiences. I know you've had a personal, um, feelings about, you know, you can go into much detail as you want in this, in this kind of area about your ownership.

[00:09:24] Sickness disability. I know that we, we have such a dark sense of humor anywhere. I think that's probably the way that we cope about things. We have to make jokes about some of your experiences. Um, and I wondered whether you wanted to talk about the nuance of, cause I feel like you've transitioned in various ways of experiencing.

[00:09:50] You know, so like a thing that people really understand and get straight away and then going into other things, which is more nuanced and, and there's a different kind of societal heaviness over it. Um, so do you want to talk a little bit about that? Do you

[00:10:03] **Pippa:** mean the cancer glamour?

[00:10:06] **Suriya:** I didn't want to say the concert level, but I did most thinking about it.

[00:10:10] Yeah.

[00:10:11] **Pippa:** Um, yeah, and I think there's, there's loads in it. So, yes, I had cancer twice. Um, and that it has been part of, but not the only thing that has left me in a position where I now have considerable barriers to sort of just moving through life in the way that I used to. I'm not able to just move through in the way that I used to.

[00:10:35] Um, and there are considerable barriers now. And. Medications and needs essentially. Um, and I fought a lot about, cause cancer's like a really magical words, which I'm aware sounds a little bit like we were, uh,

[00:10:56] **Suriya:** yeah. And I feel like in a way we find the lessons it's like, of course, like if you've had cancer or, um, And have anyone in your life who's who's had cancer or like died from cancer if it's horrific disease and experienced to go through.

[00:11:15] Yeah. I cried in this car. Yeah. And in this context, we're talking about the relationship, the way where the experience of having cancer in society. Societaly how. Weird strange feeling of like privilege affords you. It's such a strange way to, to experience it. But I know that when I was speaking to, um, imaging on the, on near the episode, we had the same experience, even though, even though they haven't experienced cancer, they were, they were like, we're not going to say it, but we're very thinking, what is that?

[00:11:50] That feeling of like, This particular space gets a lot of attention and other spaces, but I know you've had your own experiences because of things that have happened after that. So,

[00:12:00] **Pippa:** yeah. And that's it, right? Like it's about space and, and like room for dialogue. And so, and that's, you know, it's not, none of what I'm about to say is to minimize the experience of cancer.

[00:12:13] I've had it twice. It's disgusting. I watched my mom die of it. It's not, it is a terrible disease. Brings no real joy. Um, but it is also a disease that is incredibly. Well funded and researched and understood. Um, um, and we, you know, we run up mountains, we jump out of airplanes, we'll climb down the side of buildings.

[00:12:40] We'll walk into smiles, we'll do all of these things for cancer. Um, and partly that's because it is actually like not very unusual. Um, you know, like the ident, the IDN on channel four when they're doing standup to cancer, I'm not sure if I'm allowed to say any of that on a podcast short it's fine. Um, is, you know, wanting to have us will get cancer.

[00:13:01] And I always joke with my partner, I'm always happy. So I got that one covered, covered off in this households. Um, You know, it's a really, really common sickness, but also there are many, many, many different forms of cancer. Uh, my experience of having one kind of cancer is very different from the next person's experience of having an entirely different form of cancer and their treatments are different.

[00:13:25] But what I noticed really quickly was like how powerful the word is, like how you say you've got cancer and people will do things. They will really do things. They will bend over backwards. They will help, they will support. They will, you know, they'll tilt their head and widen their eyes and, and basically do whatever you need them to do.

[00:13:47] Um, and that experience then changing, shifting into a period of time when, uh, I was essentially in remission from cancer. So I wasn't, uh, you know, I had had surgery and chemotherapy, but. That treatment cycle and series had left my body lessened, um, and considerably less able, um, that was really weird to try and cause then suddenly I didn't have this powerful word because also when, when you learn quickly, when you have it, like how powerful that word is, it's also using it really carefully and responsibly.

[00:14:27] So. It scares people like it's still got, you know, there's still people who will call it the big C to me, which I'm just like, I mean, come now if we're too scared to say the word where me and you are not going to have a proper conversation, um, you know, like people find it really, um, really scary, really, really scary, uh, I can't say, oh yeah, I've got a, I've got a difficult buddy.

[00:14:54] Cause it was ravished by council treatment because actually like I'm a few years out of treatment and see like when I meet new people, they don't necessarily need to hear that word and she'd be like, oh my God. Oh, but you're so young and all of those things. Um, but that, that's the reality of my situation.

[00:15:16] So now I don't have. A label for it. Like really what my, what I'm managing. It's not a, it's not one condition. It's a, it's a collection of. Collateral bodily damage from very extreme treatment over to two episodes of cancer that also intersect with a lung condition. That's completely separate from any of the cancer that then is drawing and, and kind of, so all of these things, and I think that that's the thing, right.

[00:15:47] Was sickness. I think a lot about like flows. I'm doing a water movement, like, like a way, but no one can see it, but like the ebb and flow. Of sickness I think is different to the ebb and flow. Maybe of disability.

[00:16:08] **Suriya:** Yeah. Oh yeah. And definitely some disabilities. And I saw, and I saw. Someone was talking about that actually, in terms of the positive sides of highlighting the intersections in the disability and the sickness community and, um, and the long-term health conditions and chronic illness, if that some people will have conditions that are quite stable.

[00:16:30] So even though they still experienced barriers in life, it's a different experience to those who. It's it, you, you D you know, you don't really know whether it's going to go up or down, or when you're next going to be in hospital for an operation or learning something new, how to use a new equipment or whatever it might be.

[00:16:53] And I think I just thought it was really important for, and thank you for sharing your experience of, of going through cancer and then still living with the effects. Um, kind of all the treatment that you experienced. Cause I think that narrative specifically around cancer is the battle and it's like the binary of like you have cancer and you win it.

[00:17:15] And it's like, woo. And it's like

[00:17:17] **Pippa:** the reality.

[00:17:23] **Suriya:** Oops. I think it's that thing of, it's really important that we talk about this because I know that maybe. You know, we know that the relationship between shame and sickness and disability and how closely linked it is because of society's experience of, you know, overcoming disability or overcoming sickness.

[00:17:46] And then if you don't, for some reason, it's your fault, do you know what I mean? Or you're not strong enough where you didn't push hard enough or whatever it might be. And, and the fact is I know that there's people out there who might be listening today, who maybe still experience. Exhaustion after having a treatment for something that, you know, the doctors TikTok off and said, you don't know, but actually they're still living with that.

[00:18:12] And maybe a silence in themselves, not able to express what they might need in life in terms of access needs or in terms of in the doctors, because it's like, oh, well, no, I should have they tick me off now. So I should, I should be fine. You know what I mean? I should have

[00:18:27] **Pippa:** survived.

[00:18:28] **Suriya:** I survived. Yeah. And I think it's actually really interesting when I was listening to this, um, disabled, um, activist who I need to find the name of.

[00:18:44] Cause it's really important that we kind of credit people. Um, but they were basically saying that the pandemic. The way it's been kind of, um, phrased is almost like it's about life and death. So it's an activist called whose, um, website is crutches, crutches, and spice, and they are based in, um, the USA. The name is

[00:19:15] Bobby grin. And they write from the perspective of a black woman with cerebral palsy. I've been following the money, um, for awhile and they talk about the experience of disability. And I'm really outspoken about, um, the politics of disability. And they were talking about, um, the pandemic and how it's being treated as like a life and death, um, epidemic, like it's, it's about death and actually.

[00:19:40] It's also a mass disabling event because there are lots of people who in our league living with long COVID. There are lots of people who may be, they've got like, um, further mental health presentations because of the reality of, of living, um, within lockdown and all those things. So that's the, that's the nuance that's missed out of the idea of like, just because someone survived COVID if they're in intensive care and they came out doesn't mean.

[00:20:09] That now it's all over it. You know what I mean? There's lots of things that might happen as a result of any kind of illness. And I think, um, I think that's why we started. Sickbabe really it's about that, that life in between. Really?

[00:20:23] **Pippa:** Yeah. It's, it's really interesting. Say like survivor culture. I think my cancer is the king or queen of that.

[00:20:30] Like I think that the champion there, the. The leader, I feel like, um, that survivor culture is really, really embedded into cancer in particular. Um, and you're like a survivor and a hero or you like a tragedy and an inspiration, or you can be an, you can be a survivor and be an inspiration, like what you can't be.

[00:21:00] Is sort of not recovered, um, but also not sick, you know? That space, the area that sits in between, well, I'm not sick with cancer anymore, so everyone, everyone can breathe a big sigh of relief because I've survived. It. I've

beaten it, me and cancer. We went to war and I won the war. Well done me. Look at me.

[00:21:23] Here's my survivor barge. Give me a mentor. Everyone called me an inspiration. Lovely. Like actually, like I'm not. Like, I've not, I didn't die of cancer, but it has considerably impacted me. The likelihood of it coming back is probably quite high. Um, genetically for me personally, and said we're not done. And the outcomes of it is not done.

[00:21:50] Um, So maybe I'm surviving with it, but I have not survived it. Um, but I also find that I think because my mom and I were in a weird twist of fate, we're diagnosed with comes from the same day. The first time I had it and my mom died. And so there's a tension for me about what if we're at war and I'm a survivor then what does that mean?

[00:22:21] And what does that mean and what will it eventually potentially make me? And can we just lay down that language? And also, can we just recognize like the hundreds of thousands of people who are living with really long term cancer? Like I know two people who are alive still, but a third person, I know who I have been managing cancer.

[00:22:45] For people actually four years, like, and some of them decades, like long slow-burning constant relationships with the doctors and the hospital to manage it. And so just assuming that we're either all bald, you know, and very grateful for you running your marathons or jumping off. Airplanes or whatever, or we'd be an it.

[00:23:10] And we'd find like, actually that isn't for me, that isn't a true picture of, um, that is some of the cancer stories and experiences. It is not the full spectrum. Um, but I just don't want to think that it just dominate so much, right. Like if you think about fundraising and charity, There's so many conditions that people don't even know the name of, but because it's such a well-known and well documented illness, like people feel really able to give to it.

[00:23:43] So actually, like it's sort of incredible the amount of money that is in cancer research. Like it's a huge, huge business, you know, like, um, the, I often wonder. What it might look like if we spread some of that money out across different conditions. Um, more even me, you're getting into really dangerous territory here.

[00:24:08] Like there's definitely going to be some people that hate what I'm saying. I'm sorry. It's just

[00:24:14] **Suriya:** my experience. But also it's informed by your real life lived experience. Isn't it? Do you know what I mean? And actually it sits such. Admirable for you to, to say, Hey, I'm someone that actually benefited quite a lot from all those re those fundraisings and all that kind of stuff, but still I'm able, I still would like to question it, think about what, you know, and I think largely of that has become out of some of.

[00:24:39] Um, well, I mean, it's you as a person anyway, you'll never, you would never be that kind of person who wishes like I, and benefit from it. So forget everyone else. Like winner, winner, winner, chicken dinner, like pack it all in don't raise money for anything else. Do you know what I mean?

[00:24:59] It is interesting. Cause I I'm kind of on the other side having a brain condition and I, when I've been doing some reading about this. And some of the historical context of disabilities associated with brain trauma or Brain, um, congenital conditions and how kind of in the Victoria. Era anything that was to do with what someone feared that might make, you might have an impact on your quote, unquote intelligence or D you know, have an impact on the way you look or move, um, often is, is not, um, you see how that impacts how people will research into it or.

[00:25:48] Or celebrate it or talk about it even more because it's kind of like, oh, but you can see that kind of really horrible. Um, we said to people that this is like a funny podcast, fun, and I was going to use the word eugenics, but you know, like

[00:26:08] it's not, I don't think, but it has, it has. It's not eugenics, but it has the flavors of that from historical contexts of like, who do we want to save and who do we not really care about? And who do we think deserves quality of life and who do we think, um, shouldn't and should be kind of hidden away and not, and shouldn't actually have anything done for them kind of thing.

[00:26:31] So, um, So I have a condition where, when I say the name, no Heart, even doctors and nurses don't know what it is and kind of thing. And that is the power of come campaigning and fundraising, which means that things are more readily in people's minds so that they. What it is when you say it. And I've realized when I was younger, I didn't really get why, what these campaigns are for, or why we needed to be having the adverts on TV or anything like that.

[00:26:55] But now I'm like, oh wow. If, if that was always in people's language, it would have an impact on the way that I experienced work. Um,

doctors, everything, because people would have, oh, that thing I know from the Advil, from

[00:27:08] **Pippa:** when I said I've got. It potentially could to have the same impact. Whereas if you say I have, here's a word you've never heard of in your life.

[00:27:18] And they can even say back to me, then it just doesn't do that same thing. There's something really interesting in what you just said about like what we choose to research into and what we don't. And I think that's probably, there's some really interesting questions for me about what, how much of that historically has been really roots, rooted in nations of shame.

[00:27:40] Um, like what you were saying about things that change, how, how people's brains work or how like they look and appear and like how, where, where we choose to put priority is really interesting. But what I would say is like, I think we definitely all are aware of what cancer is like. So I'm really interested to.

[00:28:05] For us to broaden our understanding of a much wider range of shit people have to live with, I was going to say conditions, but then I was like, gosh, such sanitization, like shit, people cope with stuff that people handle, stuff that people live with, you

[00:28:20] **Suriya:** know? Yeah. And also it's interesting. Cause even like, because when we're talking about language, we're talking about cancer, we're talking about sick, disabled, all these different things.

[00:28:31] It's. A mentor of mine back in the day, said to me, and enabled disabled as well and said, you know, sometimes you might actually what you have to think. What are the words that you use that make you feel most. Empowered and also are able to communicate what you want to communicate in that moment. Um, so I was talking to them about, um, my conditions and saying, this is how I normally say it.

[00:28:58] And, you know, sometimes I feel exhausted because I feel like because people don't know what it is straight away. Like I have to write a whole list of, of, um, of, of symptoms or whatever it might be. And he really helped me see that he sees. From his experience of living with disability. I think he'd lived with it for quite a long time, maybe potentially from birth.

[00:29:20] Um, When you say medicalized terms, often people blank over go into a state of fear and shock, worry. Even with cancer. It's like, they're like, oh gosh, they know what it is, but it's straight away. Oh, Ooh. I got like a straight worry. They get fear. They might, they remember the person that they know about it.

[00:29:41] They, it triggers a lot of things in lots of people. So rarely do people hear. Uh, medical term and go, okay, cool. I know exactly what you need then you don't. I mean, like

[00:29:55] literally, so he was like, what it sounds like is what you want to say is you want to tell people what you need. I do, you always need to say your condition in order for that to be heard. And so actually in the last kind of two years of my life, I've been making the active choice really to, um, To just say, I, you know, I live with a health condition and, um, so these, the access needs that I have, blah, blah, whatever, or, you know, I, because I've, I, or sometimes I'd even say I'm living with a health condition.

[00:30:25] I'll just say, I'll get really tired. So I need to have this. And most of the time people, it just, it just minimizes, you know, some of that micro trauma that we go through on a day to day of like, oh, I've just exposed this thing to this random person that I don't really even know if I'm going to see again.

[00:30:42] And then I'm going to like, you know, it's, it's, it's, it's actually figuring out how to protect ourselves. So we don't have that awkward cause often what I do is a. Also minimize myself with jokes. So cause when I, because even though cancer, even though I don't have the cancer thing, the brain brain does the same thing makes people go, oh my

[00:31:02] **Pippa:** brain condition.

[00:31:04] So

[00:31:04] **Suriya:** people, often people often I can see them kind of searching on my face. What that means.

[00:31:16] **Pippa:** how could I tell where's your outward impact of your brain condition? Because you know, your ear slightly

[00:31:22] **Suriya:** I'm reading.

[00:31:27] I think our properly confused people, I think they're like, okay, like, I don't like their thinking, how are you talking then? I think that's honestly what I imagined that they think. Or how are you? Are you, oh, are you going to like, or it makes people feel afraid. And so, and that for me in the end is not helpful.

[00:31:45] So it's like choosing the language that we use feels really empowering. Um, and also accepting that it changes over time. Doesn't it? Um, depending on your age

[00:31:58] **Pippa:** or your needs language, both. I think, yeah. I think definitely both health condition is a bit of a trustee favorite. I left, I left with long long-term health conditions is when I roll out.

[00:32:14] It's interesting. It's often like it depends what context I'm in and how sort of much I feel I need to validate myself. I think there is like, I'm really interested in that idea of like, how do we just explain what we need? Um, without like, I find it very difficult to then not try and justify those needs.

[00:32:42] Like I'm still in that phase, which, you know, please seek grief and grief and acceptance, you know, it's all part of that cycle, right? Like, I still have to catch myself when I am starting to justify. And I always say like, sometimes I'm telling people like so much detail. I don't want to tell them they definitely don't want to fucking hear it.

[00:33:04] Like, I'm just doing this weird, like validation piece, like where I'm just like, yeah, because of this and this, and that means there's like, they don't want to know that much detail. They're not that fucking bothered. They're not that interested in my life. A lot of people like in the art sector, if you're like, oh yeah, I've got access needs.

[00:33:21] But the first reaction is for people to be a bit scared because people go, oh, okay, must get this right. It must, must meet the needs of this disabled person appropriately so that they don't get angry and say that I'm an able list on Twitter or whatever. Like there's a lot of that that happens in the sector.

[00:33:36] So actually then me, like going into like pure levels of detail because. I feel like I've got, I validate myself. It's like unhelpful for them and unhelpful for me and just waste several one's time. But there's, it's always say like, sometimes that like validation, verbal diarrhea, um, comes when I don't feel the people around me are confident in supporting or handling or responding to what I'm saying.

[00:34:03] So what happens is I keep talking, like I just keep explaining because. They look a bit blind core, a bit unsure, a bit scared. And so actually for me, it's coming from a place of trying to make them feel better about it, but really the last people I need to make feel better about my health conditions is anyone but me.

[00:34:21] Right? Like,

[00:34:23] **Suriya:** yeah. It's just, you just, you're just enabling all the external, um, like additional emotional labor that goes on to also, I think the nuance of having a. Of having an invisible health condition, which is like, it is a different set of challenges in and of itself because I think, but I think, you know, I think that fear piece that you spoke on is really prevalent for, for kind of all disabled people.

[00:34:54] I think if they see someone who walks in a room and looks visibly disabled, Because we live in enabler society, it's kind of like, Ooh, you know, like you said, it's your need to do something is driven by the fear of getting it wrong rather than the care of that person and the desire to want them to, um, be able to experience the thing fully.

[00:35:18] Um, and I think what, you know, the thing, whatever you might be doing, and I that's a generalization of course. So there are people. Who all driven by cat and buy and buy. But I think a lot of it comes down to the fact that we, most people will go, oh gosh, what? We don't want to get it wrong.

[00:35:39] **Pippa:** Fundamentally quite selfish.

[00:35:41] Right? Like fundamentally as like a species human nature itself first. Like, so even, even though like I lived the way I live. There was all the things I deal with. I've definitely had that response on occasion and gone, oh shit. I'm not sure if we've booked the BSL interpreter for this performance. So I'm not sure, you know, like I've got it wrong and I've had that reaction and I have my own set of lived experience.

[00:36:08] So like it's not, it's not an aggressive criticism or anyone that reacts that way. It's just, that's where we're at in society at the moment. And we need to keep moving to push it on further.

[00:36:20] **Suriya:** But that sounds to me what you've just done, like accountability, rather than, rather than fear-driven escapism. You know what I mean?

[00:36:28] It's a different thing. Like he's like, oh, I better do this because I don't want to get caught out. It's different to make sure that let's make sure that we've, we've made sure everybody can access this. Cause I don't want anybody to feel left out. Is it, is it

[00:36:41] **Pippa:** maybe that is a different nuance? Like there, the fear of, I'm not sure I can meet this person.

[00:36:47] And I should have done the work to put it in place versus the fear of shit I'm going to get called out. They all different things like the new ones, but they're different.

[00:36:56] **Suriya:** So, yeah, and I think, and I think that if we, if we, you know, with this podcast, with the conversations we have, we're trying to put Alec or seed into the conversations to become more part of our everyday so that people feel more comforted.

[00:37:16] We all feel more confident. One in knowing that there's people around you who are living with disabilities and sicknesses, even if you can't see it, or you don't know it or whatever, or they might have, they might care for someone who does so. It is, disability is very prevalent, prevalent in lots of people's work lives in different ways.

[00:37:34] And so, and we, and we have to kind of challenge this idea of it's something to be hidden away and, um, fear and be like, oh, actually this is a piece of work that we can do where we can create a space that it isn't. Care curiosity in terms of, oh, what does that mean for you? How, how can I support you? How can I meet your needs?

[00:37:58] Is that possible? Um, than this whole idea of like, oh gosh, I didn't realize that that was going to come up here. So therefore now I've got to bring on this idea of something that I didn't think was going to happen. Whereas if we're always already in the idea of like, oh, anybody in this room could be living with something or dealing with something or having something investigated and don't really know what it is, or have, um, self explored the idea of whether it might be something and don't yet have a diagnosis.

[00:38:29] Having that, um, that awareness is, is going to help us all. Because I think someone, I can't remember what the statistic is, but basically it's really high in statistic that we are all going to be disabled at one point in our life. And most people experienced that in old age, but you know, you might not experience that in old age as well.

[00:38:49] **Pippa:** It's like the seasons on tack coat quote, isn't it about the kingdom and the kingdom of the world and having possible. Most of us. I can't remember the exact quote that most of us have passports for both, but maybe don't need to use them all the time. But the likelihood is that at some point in your life, at some point in the spectrum of your life, you will visit the kingdom of the sick.

[00:39:14] Um, like you won't, it is incredibly rare to go through an entire life without, um, experiencing that, that space. And I think that. Some of us are living in that kingdom on permanently than others. Um, but also that perhaps when I first entered that space, it's really different to how it looks now. And now I can see beauty and joy and love and care, and those are brilliant things in, in that space that when I maybe first arrived.

[00:39:55] Into the kingdom of the sick. I just felt sick and tired and angry and hurt and in pain. But if you reside in that space for long enough, some of that maybe transforms into care and love and joy and like from a place of starting point, that is complicated. Right. But yeah. There's almost a blitz, the grief and acceptance, isn't it like, I've accept.

[00:40:31] I've accepted my place in that kingdom now and say now, and I've grieved for the kingdom of the well, and so now how do I, yeah, like does going through that cycle, allow me to see different things in that kingdom that I couldn't see before. Kingdom is a really funny word. Isn't it? I just said it three times in the last few minutes and it's made me suddenly go, it's not really a right as a word, is it kingdom?

[00:41:01] **Suriya:** But I really, I felt like what you were saying. There was really beautiful in the sense of that idea that we, that we get placed in this or the kingdom and the narrative that society wants us to internalize is that we must do everything we can. To run back over to the kingdom of the world to get out, to get out.

[00:41:22] And if you don't then your lazy or you aren't, you aren't strong enough or

[00:41:28] **Pippa:** whatever it might

[00:41:32] have. You drank some fig because if you drink definitely FIC

[00:41:36] **Suriya:** fix you for. Yeah. The only thing between you of the kingdom and the second kingdom of the whale is prune juice, pepper. You knew that.

[00:41:45] **Pippa:** I think I'm find if I just become a week, a vegan for a month, then I'll actually be

[00:41:48] **Suriya:** completely fine. So yeah, definitely.

[00:41:51] **Pippa:** If I download the Headspace up and meditate every day for two hours, I'll be fixed.

[00:42:00] **Suriya:** The advice that I've had. Oh, my favorite piece of advice, um, because my brain condition is that one, like some of my brain was basically falling out of my head, which is a very simplified version of it. And, um, a family member said, well, can't you just massage it back here.

[00:42:24] And they didn't just say this to me in front of my neurons. They said, they said this in front of my neurosurgeon as well. So he was like, he was actually really, really sweet. I think he was just like, I don't. Yeah, like he took it serious. He took the question seriously, which y'all know the profession, no opinion.

[00:42:45] He probably could have just laughed it off, but. But it's interesting what people say driven by fear or by, you know, it's always good intention visit. They don't want to, but it is hilarious. I think when, when sick people and disabled people swap stories, like what's the absolute, most bizarre piece of advice you've been given.

[00:43:03] And I feel like that is my, my, um, Connie just met my number one. Just push it back in,

[00:43:16] right. Just be like you, or got a little bit of a peep into our WhatsApp voice messages and, and, um, hourly conversations that we've had over these years. It's just, um, so. If you're a Sickbabe to have those sick friends who will just get it without you having to really explain things in depth, and also say some of those things that, or you can't really say to those who haven't had sickness experiences or some of the frustrations about things that you're not meant to feel frustrated about what you do.

[00:43:46] I think what I can say that I've took from this conversation is the importance of community and finding a safe space with other people who, who

are just, just get it really and are able to, to hold you in, in those moments. And, you know, as Sickbabe we have those moments repeatedly and we have to hold space for you.

[00:44:08] In those. So you can find more about pepper, um, via her website at [www dot HIPAA, chris.co.uk](http://www.dotHIPAA.chris.co.uk), and follow some of the work that she's doing. And all the amazing artists actually supporting baby was produced by. She wants a dog supported by contact theater and arts council, England sound designed by the amazing and Leon Evans.

[00:44:35] Follow us on Instagram at Sickbabe pod. For more information.

[00:44:46] Um,