# Toxic Shock Syndrome

[00:00:00]

**TSS Firsthand:** Hey y'all, I'm Autumn. I'm a longtime listener and I am really excited to share my story. So when I was 18, I was hanging out with my boyfriend at the time at his house, and I was on the last day of my period, so I was wearing a size light tampon. It was about 10:00 PM and I was at that eight hour limit of my tampon, but he did not have a trash can in his bathroom, and I was also really scared of his mom, and I did not want to venture to the kitchen trash.And so I figured that I would just change it when I got home. My midnight curfew came around. I went home and changed my tampon, and then I went to sleep. Woke up at 8:00 AM to change my tampon again, but now I was feeling a little bit woozy and I had this like itchy red palm rash. Uh, for bit of context on this next part, I also have a condition called hereditary angioedema, which can often look and feel like an allergic reaction, even though it's not.So I figured that I might have been having an HAE attack in my hands, and so I used a dose of my HAE medication, then I went back to sleep. You could equate it to maybe in a non-HAE patient, if you wake up, you feel some allergic discomfort, and then you take a Benadryl or something. I woke up again at noon as teenagers do on the weekend, and I just felt so nauseous and I was lightheaded and feverish and just overall real cruddy.

I crawled down the stairs with a blanket and I laid on the couch to watch TV, and I kind of chalked up my symptoms to just random illness, and I figured that I'd be better tomorrow. I've had this bad track record ever since I was little of having these wild and just incredibly harsh bouts of strep throat, often bad enough to go to the emergency room, and they would happen so suddenly and make me so sick that I could just be on death's doorstep today and then just be fine tomorrow.If I have antibiotics, of course. And I've also struggled with these just seemingly endless infections of staph and strep bacteria on my skin, in my ears and in my eyes for just about my whole life. And me and my parents thought that this illness was just one of those situations, or at least the flu because it was January, and we really didn't think much of it until my hand rash was so bad that I could no longer hold my Gatorade. And it really wouldn't matter anyway 'cause I could not keep my Gatorade down. And it got to the point where I vomited and I threw up down my front and on the couch, and I could not even like move to not throw up on myself. And that was when we went to the ER. It was about 4:00 PM when we got to the ER, and then by 7:00 PM which was just 18 hours after removing "tampon zero", I was in the ICU with a blood pressure of 52 over 28, a scorching fever, and then either racing heart rate or a slowing heart rate,

I really cannot remember, and then the gradual shutdown of my bone marrow, kidneys, and lungs. And it was obvious that I was in septic shock, but no one could figure out why. Um, and then in my feverish haze, I remembered all of the warnings about toxic shock syndrome on tampon boxes, and I told my doctors about what had happened with the tampon and the trashcan. Toxic shock syndrome really wasn't on anyone's radar, and nobody working in that hospital had ever actually seen toxic shock syndrome in person before. But that's what I ended up having. Five days of hospitalization, my first ever pelvic exam, and catheters. Awful. And enough lines and antibiotics to take down a horse, I was discharged. Um thanks to early intervention, quick thinking, and then hospital staff intent on solving a mystery, I'm still alive today and I'm lucky to have not lost any limbs or organs due to tissue death. Um, the worst that I personally have in recovery was about a year of being immunocompromised and having to slough off all of the skin from my palms and soles and mucous membranes due to cell death, which is just about the grossest mental image you can muster. But I guess it's the price of being alive. And now that it's 10 years later, I'm really open about menstruation and what we can do to prevent TSS and who might be more susceptible to contracting TSS. And I love to talk about the need for free access to menstrual products and access to disposal methods in all bathrooms, public and private. And as a person who now works with teens, um, I love putting my experience and advice to use in the hope that young people, even if they never have a run in with TSS, will not treat menstruation as a taboo topic because I'm living proof on how treating things as taboo can just be a little bit deadly sometimes.

**EW:** Yeah, [00:05:00] absolutely. Terrifying.

**EAU:** Yeah. Yeah. And to be the one who has to tell your doctors, by the way, could this be, could this be toxic shock,

**EW:** gosh. I mean, it just is like, I, yeah. And then especially, 'cause I feel like there's that sense of, I don't wanna tell someone their, like, their job or be like, you know, I don't wanna be like, oh yeah, I was on, um, I was on WebMD and this is what I think. But like, it's, it's real, right? Like you have to speak up and advocate and ugh.

**EAU:** a hundred percent. I'm a huge fan of people telling me what they found on WebMD. It's very helpful.

**EW:** love that. I love that. Um, well Autumn, thank you so much for sharing your story with us.

**EAU:** And we're so glad that you're okay.

**EW:** Yes.

**EW:** Hi, I'm Erin Welsh

**EAU:** And I'm Erin Allmann Updyke.

**EW:** And this is, This Podcast Will Kill You.

**EAU:** Welcome to Toxic Shock.

**EW:** Shock. Um, I am, I, this is, I feel like one of those, I know we'll get so much more into the weeds, but I feel like this is one of those diseases where awareness around it is so much higher

**EAU:** Mm-hmm.

**EW:** the incidents of it, but it also, that means there's like, it's a double-edged sword, right? Like there's mean that there's more fear around it, but also we can recognize it when well, yeah. Okay. That's fair. We're more likely to recognize it if it happens. Yeah.

**EAU:** I have, I have so many questions for you, Erin, about like, how we first saw this and like all of the, I I saw little bits and pieces of what happened in the late seventies, early eighties, and like, I, I just have so many questions still, and I'm, I'm really excited.

**EW:** you want me to go first?

**EAU:** Kind of, but

**EW:** We could give it a go.

**EAU:** it would be fun. It's just on the fly.

**EW:** on the fly. Well, I guess before we get into literally any part of

**EAU:** Mm-hmm. Mm-hmm.

**EW:** it's quarantini time. What are we drinking this week?

**EAU:** drinking shock tactics.

**EW:** I could hear the pause, like, wait, is it

**EAU:** Like, what was it again? We just went over

**EW:** literally just talked about it, uh, is shock tactics. Yeah. Um, and it's, it's, we're doing, honestly, we're doing like a make your own quarantini if you want, but the standard recipe is the placeborita version. So good. It's sour cherry syrup. Like sour cherries. They're the best.

**EAU:** Yeah. Aaron, before this was like, where am I gonna get sour cherries? Gosh, they're not in season on my tree yet. And I'm like, dude, they're frozen. They're frozen section.

**EW:** I do love the, I mean, yeah, and I feel like my, I, my trees produce enough to make one cobbler

**EAU:** They will keep getting better. Before we moved from when we moved, like from Illinois back out to California, the tree that year had the best year ever and we had so many still in the freezer. By the time we moved that I made a huge slab pie to take with us on the drive and

**EW:** remember that.

**EAU:** that. We ate. I think we gave some to you when

**EW:** I think you did. Yeah. Uh, so sour cherries,

**EAU:** It's sour cherries.

**EW:** then you can take the sour cherry syrup, add some club soda and a little bit of lime, and it's like refreshing, delight.

**EAU:** So delicious.

**EW:** delish, and we'll post the full recipe for that placebo, Rita. And then you can make your own quarantine on our website. This podcast will kill you.com and on all of our social media channels. If you're not following us, you should. You should also follow exactly right on YouTube, so you can see the full video of this and a lot of our other newer episodes.

**EAU:** It's quite exciting stuff.

**EW:** is.

**EAU:** Um, also, you can check out our website if you haven't done that already. It's called this podcast achille.com. And on it you can find such incredible things, including merch, um, including, uh, all of the sources from all of our episodes, links to Blood Mobile. Who does the music, our good reads list, a uh, bookshop.org affiliate account, our Patreon page. Hi, the list goes on.

**EW:** goes on.

**EAU:** Check it out. This podcast affiliate.com.

**EW:** Yeah.

**EAU:** If you haven't already rated, reviewed and subscribed, uh, you can do that. Um, we'd love it

**EW:** Time for toxic shock

**EAU:** shock syndrome, okay.

**EW:** Okay. I'm, I'm, I'm gonna have you go first because I feel like it'll help me tell my

**EAU:** It will, it's like the way we do

**EW:** the way we do it. Yeah.

**EAU:** right after a quick break.

**EAU:** Toxic shock syndrome or TSS is a disease. It's called a syndrome because it was like just a collection of signs and symptoms before we knew what caused it. But now we know exactly what causes it, [00:10:00] and it's caused by a toxin, or rather, a group of toxins that are produced by two old time friends of the podcast that is Staphylococcus Urus or Streptococcus Pyogenes or Group A strep.

**EW:** okay.

**EAU:** So Erin, I

**EW:** I was like, I Already have a question.

**EAU:** off the bat. Um, I thought about, as I was putting this together, I was like, I should probably check in with Erin and see if she's doing the history of like staff TSS or strep TSS. But then I was like, I don't care. I'm gonna do both.

**EW:** great.

**EAU:** Okay, great.

**EW:** I think I'm doing staff TSS?

**EAU:** what I assumed because that is more related to like menstrual TSS, which we'll talk in a lot of detail about, but we're gonna talk about both. So there's staff associated toxic shock and then there's strep associated Toxic shock.

**EW:** Real quick, this is just, is a minor question.

**EAU:** Uhhuh, give it to me.

**EW:** it should, yeah. Toxic shock. It's no longer called toxic shock syndrome because it's not a syndrome

**EAU:** no it totally is still called Toxic Shock syndrome. Yeah, yeah, yeah. It's just, that's how it got its name initially,

**EW:** Yeah.

**EAU:** but it's still called that.

**EW:** Okay. Well, I thought because you said that. Because it's, it's, we know what causes it. We know all of this, that it was initially called a syndrome and now

**EAU:** No, it's just that like some people who are into semantics are like, it's not that accurate anymore, but like it's still what we call it. Yeah,

**EW:** There are more important things to worry about

**EAU:** Right. Aren't there

**EW:** Yeah, I think So Like toxic shock.

**EAU:** toxic shock. Syndrome, disease, whatever. So toxic shock, it's caused by toxins, released by staph or strep. And these are both gram-positive, really cute little ball shaped bacteria. And the most famous of the two is staph TSS. And that's because that is the one that is more strongly associated with menstrual and tampons. With menstruation and tampons.

**EW:** Yeah. You just mean like infamy or do you mean like sheer number of

**EAU:** No, I mean infamy, not sheer number of cases as we'll get into later. Um, but we're gonna kind of talk about all of these because the mechanism is really quite similar in all of these instances, whether it's menstrual associated toxic shock or non menstrual toxic shock, whether it's staph or strep that produce that toxin. There are some differences in like the kinds of symptoms that we see, whether it's staph or strep, but I'm gonna kind of just focus on the similarities.

**EW:** Okay. Yeah.

**EAU:** So in any case, like I said, it really is a kind of clinical definition how we find toxic shock. And so it's a set of signs and symptoms that we're looking for. There's not one diagnostic test that says you have toxic shock, so let's go over what those symptoms kind of look like, how it manifests, because that's how we get to how we diagnose it, right? So in toxic shock, people generally start with a fever,

**EW:** Mm-hmm.

**EAU:** and this might not be the first symptom, but it is a very, very common and important symptom, and that fever tends to be quite high. So we're looking at like 102 Fahrenheit or higher. That's 38.9 Celsius or higher. The shock part of it means that there's also hypotension or low blood pressure because that's part of shock.

**EW:** Why?

**EAU:** Why does that happen? Oh, we'll get there. Don't worry. We'll get there.

**EW:** just going through the symptoms

**EAU:** We are going through the symptoms. This is how we know signs and symptoms. You also, especially in the case of staphylococcal toxic shock, we will see a rash, and this tends to be like a diffuse kind of splotchy red rash. Sometimes it's described as like sunburn like. And then we'll also see evidence, either laboratory evidence, like when we're looking at your lab results or symptom evidence of multi-organ involvement on the way towards organ failure. And so this could be involvement of your kidneys, it could be your liver, it could be your musculoskeletal system, which we might see with like pain or with laboratory findings. It can be neurologic manifestations. It can be literally any organ system that's affected. And usually to meet the criteria you have to have at least two organ systems like evidence of damage and at least two organ systems

**EW:** Okay.

**EAU:** when it's streptococcal toxic shock. Almost always, you will find some kind of initial infection, some kind of initial invasive infection, like a necrotizing fasciitis or a cellulitis or evidence of a bloodstream infection. So growing this streptococcal bacteria in your bloodstream

**EW:** Yeah.

**EAU:** with staph, you might not very often you do not see an initial infection, like a cellulitis or something that kind of precipitates this. And with staph, only [00:15:00] about 5% of blood cultures are positive for staph reus

**EW:** Okay.

**EAU:** compared to like 60 to 80% of blood cultures being positive and streptococcal toxic shock.

**EW:** Okay.

**EAU:** Does that make sense? Yeah.

**EW:** A couple questions.

**EAU:** okay. Go.

**EW:** Um, number one timeline of these, of these signs and symptoms, like, does it start with a fever? Like at, at what point does it Go. From, you know, not so great feeling bad rash to shock, multi-organ involvement.

**EAU:** it is such a good question. I don't, there's not a good, I don't have a good number for you in part because it's gonna differ, you know, if we're talking streptococcal versus staphylococcal, right? Like if it's an infection, how quickly does it go downhill? It really depends on the infection with streptococcal toxic shock, which very often might not have, you know, evidence of an infection necessarily,

**EW:** Mm-hmm.

**EAU:** because there's not necessarily evidence of infection. We don't have this like traditional incubation period where you like, oh, might have this amount of time, or how long does it take? But what I will say is that once this has started to develop, so once you see this evidence of like fever and the blood pressure starting to go down, this process can happen very rapidly. So you can see signs of organ damage and rapidly worsening clinical status within like 24 to 48 hours.

**EW:** Okay. Um, that's very fast And

**EAU:** It is.

**EW:** Another question then. so related to the blood cultures, can you also screen for the toxins themselves? Like is that the way that people look for this?

**EAU:** You, so you could, um, if you. If you had the capability to do that. So if you had like the right PCR based testing or whatever it is, um, you might, you might a not have that capacity or you might not think to, because if you can't, like if you haven't detected any bacteria, then how Do you know what toxins to look for and that kind of a thing? So yeah. So I don't have a great answer for that. But what is really important, because we don't have a great test for it, is that we do have to show that there's no other infection, right? So part of the definition, especially for staphylococcal toxic shock, is that you have to show that there's no Rocky Mountain Spotted Fever, there's no leptospirosis. It's not actually measles, it's not meningitis. Like you have to rule out all these other things before you can say that this is toxic shock. But here's where it gets even more interesting, especially when we talk later about the epidemiology. Part of the case definitions in the literature and per the CDC for staphylococcal toxic shock is that one to two weeks after this initial presentation, people develop a new kind of rash, uh, where the palms and soles of your hands and feet just kind of, the skin rubs off. It's called a desquamated rash.

**EW:** Yep.

**EAU:** But that means that that definition can only be met retrospectively, right? And so it, it's a complicating factor and probably leads to part of why we likely see an underreporting of toxic shock, because these are like, kind of messy criteria, right? And a lot of other things could potentially fit into this. And so we don't have great numbers. That's a spoiler alert for, for the future of this

**EW:** Yeah. Hey, shocking. Wow. I really didn't mean to do that. Um, okay, so Staph Aureus is, often a, like a part of our biome, like it's part of our mi our microbiome is, is strep. Biogen.

**EAU:** Oh, it can be definitely.

**EW:** be, Okay.

**EAU:** be, yeah. In like your throat or your nose or something like that. It can

**EW:** Throat in your nose.

**EAU:** but staff is definitely like, it is. Our friend staff lives on probably almost all of us. So how does this actually happen? How do you get from like, I don't know, staff just living on you to toxic shock? Well, let me tell you, uh, it can happen either from an infection, right? Often we see toxic shock, like I said, with streptococcus. It's, you know, a necrotizing fasciitis or some kind of infection that leads to an invasive infection. With staph, it's often seen in the postoperative setting. So it could be like a wound or an incision after an operation because staph is just everywhere. If it happens to get in there and multiply, or if you happen to be colonized, let's say in the vagina, and then you have an overgrowth of this particular strain of these bacteria that produced a particular kind of toxin. And there's multiple different versions of this toxin. The one that is again, most infamous and you'll talk about later, [00:20:00] Aaron, well, I don't dunno if you'll talk about the toxin, but the most infamous cause of toxic shock is caused by a toxin called tss, T one, toxic shock syndrome toxin. Really clever naming. But all of these toxins that cause toxic shock are called super antigens. And we talked about this idea of a super antigen actually in our Scarlet Fever episode. Which you may remember, Scarlet fever is caused by strep pyogenes. Mm-hmm. A specific strain of strep eOIs. So super antigens are proteins. They're these toxins are proteins that bacteria can make and excrete that when they get into our body trigger an overwhelming immune response. This idea of like a cytokine storm that we've talked about here and there on the podcast. And this overwhelming immune response itself in combination with direct damage that these toxins are causing, just like ripping through our cells, is what ends up causing all of the symptoms

that we see in association with toxic shock, the fevers, leaky blood vessels that lead to hypotension, dropping blood pressure, all of the damage that we see to our organs, rather, whether that's damage directly to the tissues of the organs themselves or damage to the blood vessels that are feeding those organs, right? And all of this is what results in the damage that we see and the shock part of toxic shock syndrome.

**EW:** Okay. And so it's not really about Okay. Like the toxin itself is not acting in this way. It's our immune system responding to this toxin. and so it doesn't have to be like, like I, I'm just trying to figure out why this toxin exists, and I'm assuming it's like, is it competition with other microbes? Like what's, what's going on? Do you know the answer?

**EAU:** I, don't, but it's such an interesting question, Erin. I, I didn't look into that, like the evolutionary history or anything of these types of toxins, but it's really, really, really weird. I can, do you want a little more detail because

**EW:** I do. I would love a little more detail. Thank you.

**EAU:** It's really, really. Interesting and weird how these toxins work. And, and the question of like, why do they exist? Ah, it's so, so interesting because here's what they basically do. Uh, we're gonna step back a minute to talk about like what is a typical immune response, right? We get exposed to various toxins or antigens like all the time, right? And in our typical immune response, we have these cells that, these cells that go around and find these antigens, right? Antigen presenting cells, they usually process them in some way. And I, we've talked a lot about our immune response and this podcast before, and we've kind of glossed over this part because it's just what they do, right? They kind of take them in and they like break them up and they're like, beep it, bop, let's find the part. And then they present those antigens to our T cells who then decide what kind of response to engage in. Do we do inflammatory stuff? Do we do antibody stuff? Whatever. Okay. So these antigen presenting cells are like a mediator. They are the ones who take all the antigens and they decide like, which parts do we show to T cells? Like how are we gonna start this process? Right?

**EW:** they're making these decisions.

**EAU:** They're organizing, sorting through things. What super antigens are doing is bypassing this process super antigens. They themselves go directly to the T cells, grab a hold of these T cells, and then grab a hold of these antigen presenting cells and bind them together, like bridge them. And they're like, let's

get this party started. And that causes this massive immune response. And I was trying, Erin, 'cause you're so good at analogies.

**EW:** Oh no. The number of times that we've been like, this analogy doesn't need to exist. This analogy has been taken too far.

**EAU:** I know, but I love that. Okay, so I tried so hard to come up with analogies for this. Here's the best one that I could come up with. It's so bad. Okay. Super antigens are like the loudest guy at the party. Like the one that you didn't really mean to invite or like didn't actually want to come in, made it straight to the DJ booth somehow

**EW:** Oh no.

**EAU:** And then like opened all the doors and everyone's just rushing in. The bouncers didn't catch him. Something like, that's my analogy.

**EW:** my God. Okay. So it's like, it's like those high school parties, know, where it's like, oh, just a few of us. And then unbeknownst to The the host, friends have invited all of

**EAU:** the whole school and all of the other schools. Mm-hmm.

**EW:** and they're just run through the doors.

**EAU:** They just run through the doors. So it's this overwhelming way too expansive immune response. Do you love that

**EW:** I'm stressed about it because those, scenes in movies always stress me out. ' Cause i'm like,

**EAU:** me too.

**EW:** you're gonna hurt the house. Like, what [00:25:00] about this, Who's spilling on the carpet?

**EAU:** like every teen movie you've ever seen, that's a superantigen

**EW:** I was not cool in high school. If you can imagine

**EAU:** I think I went to my first high school party when I was definitely in college, so

**EW:** I was one being like, are you using coasters? Do you need a coaster? I've got, I've got a little basket of them.

**EAU:** oh,

**EW:** even my house, but I

**EAU:** Right. No, but you knew where the coasters were,

**EW:** yeah. Anyway. Yeah, so I can see why super antigens would be a real pain

**EAU:** A real pain. Right. And to give you more of like a numeric sense of this to see how much these super antigens are overdoing it, um, regular antigens, like just your typical ones, activate about 0.01% of our T cells on average. Okay.

**EW:** 0.01%.

**EAU:** A very small proportion of our T cells are being activated by any given antigen that we're exposed to. Super antigens are activating five to 30% of our T cells. Bye now.

**EW:** Okay. What, what, so scar, scarlet fever, and other super antigen, what about. What makes a super antigen a super anti, like obviously we know the characteristics

**EAU:** Right? Mm-hmm.

**EW:** what, is there a range? Is there a spectrum of, of antigenicity from not very, I mean obviously, but to super antigen. Why? Why? I guess it's just the question.

**EAU:** a question. Erin. It's a great question.

**EW:** Okay. Thank you so much.

**EAU:** Yeah. I don't know though,

**EW:** Ah, fascinating. Okay.

**EAU:** it? Uh, so yeah, so I mean, that, that is toxic shock and that is, you know, how it happens. Um, and why, like what is going on in our bodies in terms of the pathophysiology?

**EW:** so question about the two different. Strep and staph toxic shock. Um, is there a difference in case fatality rate? Is there a difference in treatment and management? And is there a difference in like, susceptibility again in the future to it?

**EAU:** Hmm. Such fun questions, Erin. Case fatality. Definitely. Let me scroll in my notes. Case fatality rates for streptococcal toxic shock are very depressing. Anywhere from like 30 to 60%.

**EW:** Okay.

**EAU:** Very, very, very deadly. And remember that streptococcal toxic shock is very, almost always associated with some kind of invasive infection. So the treatment requires that you identify what that infection is. You try and get like source control if you can. So that means if there's like a necrotizing fasciitis, you have to debride all of that dead tissue that is completely overrun with bacteria.

**EW:** Mm-hmm.

**EAU:** Um, and then you need to also treat the toxic shock, which I'll talk about in just a second with staphylococcal toxic shock. Um, the case fatality rates really can vary and most of what I saw estimated that the majority of staphylococcal toxic shock cases are actually not menstrual. And we'll talk a little bit more about what that means, but they're actually more likely to be, I. Something like a wound related or a postoperative infection. Something like 60% of staphylococcal toxic shock is from that rather than from menstrual sources. Um, the fatality rates, I've seen a real range anywhere between like eight and 20%, but most places also say that menstrual toxic shock is very rare to cause fatalities. And I don't know if that's just based on like current data or if that has been true historically as well, but that is what all of the literature that I read suggested.

**EW:** Interesting.

**EAU:** Yes, it's very interesting. And is that because of, you know, like demographics Because people who are getting maybe wound infections or operative infections are maybe like older or have more comorbidities or something like that?

**EW:** in some way.

**EAU:** Is it because that they also have this infection that you're dealing with, where most of the time with menstrual associated toxic shock, there's no infection. So like 10 to 40% of menstruating people just have staph aureus in their vagina at any given time. And the amount and quantity of different bacteria really changes during your menstrual cycle because of changes in the pH and things like that with menstrual blood and all that kind of stuff. And I said that it's only certain strains of these bacteria that produce this toxin. It's estimated that like 18 to 25% of strains of staph aureus across the board have the gene that encodes for this toxin. But even then, not [00:30:00] all of those bacteria, even if they have that gene, are going to make the toxin because the environment also has to be right to induce them to actually make that toxin.

**EW:** Right. Interesting. Okay. So they have, it's not like these are just going around producing this toxin all of the time.

**EAU:** not at all.

**EW:** and do we know what those environmental conditions

**EAU:** We do, Erin, so glad you asked. So one of the things that we know is that it has to be an environment that is aerobic. They need oxygen. Staph ORs can grow with or without oxygen. But in order to produce this toxin in strains that can produce this toxin, they need the presence of oxygen. They also need like a warm, but not too warm of temperature. They need like a certain pH range, not too high, not too low, things like that. And so conditions have to be right for this bacteria to grow to a degree. And then. To have the toxin like the gene to make this toxin and then to actually be induced to produce this toxin before somebody can even be exposed to potentially get toxic shock. And then you asked Aaron, what about recurrent infections? This is such a good question because we're talking about an antigen and we usually make antibodies against antigens, right?

**EW:** Uhhuh.

**EAU:** Something like 80% of people have antibodies against these types of super antigens, especially when we're looking at the common one, tss T one.

Most people, like if you just surveyed a random group of people, have antibodies against this, meaning that we're probably exposed to it at low levels and we're making antibodies against it. So when we are thinking about who is it that ends up getting toxic shock, it is not a simple question.

**EW:** No.

**EAU:** It is not like, oh, if you have a tampon in for too long. No, it is not anything near straightforward because there has to be the correct environment. One to 5% of people are thought to be colonized in the vagina with strains that can potentially produce this toxin.

**EW:** Hmm.

**EAU:** Okay, so one to 5% of people, if we're talking about menstrual, just like focus on that for a second, then you have to have an environment that is conducive, so you need to have enough oxygen. Now, menstrual blood, blood contains oxygen, so that can increase the oxygenation level of the environment and potentially help to shift those bacteria into producing the toxin.

**EW:** Yep.

**EAU:** Tampons, as you'll talk about, Erin, are strongly associated with especially the emergence of toxic shock as a syndrome. And the thought on part of the reason why is that? Because these are absorbent materials, they contain oxygen. Are you gonna talk?

**EW:** I, mean, I'm gonna talk a little bit about it, but like, it's just like, this is the part where I still have found so, much disagree. Not, not even disagreement, but lack of clarity on, and these are the characteristics. This is how step, you know, step one, step two, step three. Is it that the, is it the tampons? Is it the blood? Is it like, is it a micro abrasions? Is it leaving tampons in too long? Is it taking them out? It's like all of these different questions.

**EAU:** And Erin, it's all of these different things, and that's the point. It's not one thing it, it is not one thing. It is an individual risk factor. Are you colonized with this? It's an individual risk factor. Do you already have enough neutralizing antibodies or not? Do you have some kind of immunocompromised where you're not? producing as many antibodies for some reason or another? Have you been exposed to this at lower levels and developed antibodies or not? What is the oxygenation level in your vagina and in your menstrual blood? What kinds of, like, how heavy is your flow? Are there micro abrasions that make it easier

for either bacteria or the toxin to get into, like pass through that mucus membrane, get into your bloodstream, how much oxygen is being contained in the tampon versus in the menstrual cup? Because by the way, there have been at least two cases reported from menstrual cup use. So I feel like especially when we're thinking about menstrual toxic shock. What I took away from all of this, and we'll talk more about it in the, like looking at the numbers of all of this and how rare this disease is, is that we need a lot more research when it comes to reproductive health and like the best menstrual products and all of this stuff. But we cannot weaponize tampons saying that like tampons are the problem here.

**EW:** Uh, well, yeah, It's It's complicated,

**EAU:** complicated. It's complicated, but it is not like the tampons are not introducing any bacteria that we know of. These are bacteria that are already present in the environment. [00:35:00] Uh, and we have a lot of data that. Like we do not have nearly as much data as I feel like we should, but I think it is in part because of how rare this disease is and how many complicated factors there are that go into this right? Like it is, it is just not as straightforward. And so I feel like the takeaway that I got is not like this is evil, this is good, but like we need more information on this and we also can't, 'cause one of the papers I read suggested as a way to prevent it? to, not use feminine hygiene products. Erin. And I was like, sorry, what

**EW:** it, I mean, that Is not a very well thought out solution

**EAU:** No,

**EW:** to put it mildly.

**EAU:** to put it mildly. Okay. But yes,

**EW:** Yeah.

**EAU:** track and probably out of order there.

**EW:** No, no. Okay. So, but to maybe get us back on track Treatment. what, what do we do?

**EAU:** Yeah, so I mentioned source control. That's gonna be important. So that means taking care of any infection that we know of. If it is a menstrual toxic shock and there is a menstrual device in place, like a cup or a tampon or whatever, removing that. And then the most important thing is using antibiotics

that are going to have ability to prevent more toxin production. And so that usually means clindamycin because that helps block protein synthesis. And so it helps block production of the toxin. but then it's also a lot of like, supportive care, right? It's fluid resuscitation, it's blood pressure support. It's broad spectrum antibiotics, because a lot of times you can't, you don't know what it is yet. All of this, takes a long time to figure out.

**EW:** act fast. Yeah.

**EAU:** Interestingly, there's some evidence for the use of IVIG.

**EW:** Okay.

**EAU:** Uh, which is like, uh, IV combined immunoglobulin from like a bunch of different sources. It's basically pooled antibodies and giving people really high doses of a ton of random antibodies. The thought is that that will help like bind to this toxin and inactivate it. Um, there's not super strong data for it, but it's in part because of the difficulties of doing these kinds of clinical trials on very small sample sizes. But there's some data that it might be helpful, especially for streptococcal more than Staphylococcal, just 'cause that's the data that we have

**EW:** Yeah.

**EAU:** and that's mostly it. Erin.

**EW:** Okay.

**EAU:** Yeah. Uh, and you asked if you can get it again, you can, uh, which makes it even that much more interesting because you can, you can get it again, even under different conditions. Um, people who have had menstrual toxic shock, especially in the context of tampon use, there has been reports that people have had recurrences without tampon use. Um, which again points to the fact that it's not just the tampons. It's a much more complicated thing than that. Um, but yes,

**EW:** Yeah. I think I have more questions, but I'm gonna, they're just gonna have to come to me, like I just, there's so much

**EAU:** I know. Well, I have questions too, Erin, because like, obviously a lot of the papers that I read couldn't not say like, well, we first found out about this,

**EW:** mean, I am literally just gonna be talking about tampons,

**EAU:** I cannot wait to talk about tampons.

**EW:** I can't wait to tell you. Let's take a quick break.

**EW:** Erin, do you remember when you first learned about toxic shock syndrome?

**EAU:** Ooh. Good question. No,

**EW:** No.

**EAU:** I just feel like in my memory, and this is not, I'm sure not correct, but I just feel like I have always known about

**EW:** you were born with the knowledge?

**EAU:** no, no, like it was like tampons, toxic shock. Like that was a connection that existed in my memory from the first time that I can remember using a tampon. And I don't know if I actually learned it that first time or if it was like later knowledge.

**EW:** I mean, that's similar to me. Like, I don't know if it was in like health class or something like that, but

**EAU:** sure it wasn't in health class for me. I mean, just speaking personally.

**EW:** I mean that's, I, I, again, yeah, I, I don't know, but I do, I do have this, this memory of being in my house in northern Kentucky, like getting my first period and reading that little instruction pamphlet that came in the

**EAU:** In the tampon

**EW:** and like in one little corner was this dire warning about this deadly disease called toxic shock syndrome that you could get from using tampons. And I feel like that made such. An indelible mark on me for years after I was like, worried, but also a little confused. Like, what was it? Using it to, again, like all these questions, it was, am I gonna get it because I used a tampon for too long, or because I took it out too soon? Like, what

**EAU:** I use the wrong one.

**EW:** shock? Yes. Should I be using tampons at all? Is that gonna help me? Like, right. Clearly. I think that the, the takeaway that I had [00:40:00] was if I got toxic shock, it was, my fault because I didn't know the answers and I wasn't sure where to get them or who to ask.

**EAU:** my gosh, Erin, that's so heartbreaking to imagine little like baby Erin being like, well, if I die, it's on

**EW:** I mean, it was just like, well, you're, if you use, because it's like, use the right amount, use the right absorbency.

**EAU:** How the heck are you supposed to know, especially when you're 16 years old?

**EW:** when you're 16 years old, if you have irregular periods, like there are so many different things where it's like, but I felt like, okay, well this is just like part of what it means to be a woman, right? Like, I have my period, now I have to deal with toxic shock. That was, I mean, it wasn't like

**EAU:** This is my lot in life

**EW:** this is my right, but I just sort of felt like, okay, like this is, this is the knowledge. This is part of it.

**EAU:** Okay.

**EW:** And I feel like the, after reading for this episode, it seems to me that this, the history of toxic shock syndrome reveals how the silence and the shame surrounding menstruation and menstrual products. It presented a challenge both in identifying the source of this deadly infection as well as raising awareness at a time when words like tampon, menstruation and period were still taboo words.

**EAU:** cannot,

**EW:** And it, I think it also demonstrates how the blame has been shifted away from tampon manufacturers who did not properly evaluate

**EAU:** This is very

**EW:** to menstruating people.

**EAU:** I can't wait. I can't wait to hear about this. 'cause I learned so much inadvertently about how little testing or standardization existed, but prior to

**EW:** Oh yeah. Oh my God. I mean, did any, yeah. Um, and so I, I really only knew the bare bones of this history before researching for this episode, and there is so much more to it. Like, like you said, I, I am, I am. I'm excited. Let's, let's start at the beginning. Okay. Okay. September 25th, 1977, Denver, Colorado.

**EAU:** Oh, mm-hmm.

**EW:** I know a girl, 15 years old was rushed to the children's hospital, delirious and in shock after a two day history of worsening pharyngitis and vaginitis associated with vomiting and watery diarrhea. On admission, her temperature was 40.9 degrees Celsius, which is 1 0 5 0.6 degrees Fahrenheit, and her blood pressure was 66 over zero. End quote. Yeah, that's what it said. I read it like eight times.

**EAU:** Oh my God,

**EW:** Yeah. She was described as having red, bloodshot eyes, a hugely swollen face, and limbs, a red scaly rash covering her entire body tender, abdomen pur pure lin. I can't, I cannot say that word, Erin.

**EAU:** it's a tough

**EW:** Okay. We know what I'm saying. Vaginal discharge and severe prolonged shock. She was described as quote unquote confused and aggressive. Like no wonder right.

**EAU:** I'm sorry that you're gonna put the word aggressive in there.

**EW:** know. I know. Confused and aggressive. Right. But like just putting yourself in her shoes, imagine how terrifying

**EAU:** Can you not just describe her as dying instead, because like,

**EW:** She was acting a little aggressive.

**EAU:** oh, just a little

**EW:** Yeah. Her doctors pumped her full of IV fluids, antibiotics, steroids, heparin, digitalis, and put her on a ventilator. And fortunately, after eight days of intensive care, she made a complete recovery except for some necrosis in a few of her toes, which ultimately had to be amputated. And the fact that her entire skin had started to slough off, but she was stable. And after 17 days in the hospital, she was discharged.

**EAU:** goodness, Erin.

**EW:** Yeah. Her doctors were stumped. They had run tests for rocky Mountain Spotted Fever, leptos Posis, Scarlet Fever, And other viral rash causing diseases, but nothing had lit up. There was something familiar about this case though, because over the previous couple of years there had been a few more just like it in children aged eight to 17. Seven total from 1975 to 1977, including one death

**EAU:** In Colorado or

**EW:** Colorado. In the ho? Yeah. That had ridden like I think, I don't know if it was like the hospital system or that hospital or like within the state.

**EAU:** Yeah. Okay.

**EW:** the doctors that had been working on these cases couldn't find anything that linked them. There was no food, no drug overdose, no exposure to an animal or a chemical, but the clinical picture was similar and resembled some of the syndromes caused by Staph aureus infections. Like scalded skin syndrome and some staph food poisoning cases, swab cultures confirmed that a toxin producing staph aureus may be the culprit. And so in combination with shock being a unifying feature of the syndrome, the Denver doctors named the new Condition Toxic Shock Syndrome in a 1978 paper. Yeah. Was it actually new? [00:45:00] Was this brand new? I mean, probably not. Yeah. There were a few other cases that people found in the medical literature from as far back as the early 19 hundreds. And, um, there was some other like ancient plague that someone proposed. It doesn't really seem to track in my eyes. Um, but one researcher, one researcher suggested that It might be like a new toxin producing strain, sort of like how we talked about with scarlet Fever against strep. Ogies went from being like super, super deadly to then not like just massive shifts

**EAU:** Shifts in. What strains. Are there? Yeah. Yeah.

**EW:** And so regardless of whether this was new or not, the 1978 paper, which is by Todd et al, if you wanna read, it, was a critical milestone for toxic shock syndrome besides giving it a name. They also set out this clear clinical picture and described a general patient population. And so other physicians who happened to read this article began to connect the dots in their own patients, starting with physicians in Wisconsin and then Minnesota, and then gaining enough momentum that the CDC got involved with what was rapidly becoming a public health crisis. The first morbidity and mortality weekly report on that featured toxic shock syndrome was published in May, 1980. With these additional reported cases from these other states, researchers zeroed in on a toxin producing strain of staph aureus. Like that seemed to be behind it all behind these cases. right. But the root of transmission was still unclear. The CDC initiated a study to find out how people were getting sick with this condition, and they identified about 50 women who had toxic shock syndrome and 50 women who had did not matched by sex geographic area age, and were often friends of the cases. So they were like, okay, what is different about these two individuals? Let's match them

**EAU:** yeah. Love it. Case control.

**EW:** There we go. And then using phone surveys, importantly conducted by a woman, EIS Officer Katherine Shan, because I think that was a really crucial part of getting people to actually, these women to feel like they could open up

**EAU:** actually talk, yeah.

**EW:** Yeah. Um, they asked a million carefully awarded questions about their lives, including menstruation and use of menstrual products, and a tentative pattern began to emerge. The people developing toxic shock syndrome were young, otherwise healthy women who were menstruating at the time that symptoms developed and who used tampons. And I say tentative to describe the pattern because it wasn't really a smoking gun. There were plenty of tampon users who did not have toxic shock. But the devil, of course, would be in the details

**EAU:** Mm-hmm.

**EW:** because tampons are not all created equal. Like go to your local grocery store, uh, and check out the menstrual products aisle. Shelves

**EAU:** looked lately,

**EW:** yeah, shelves upon. I mean, I haven't looked lately because I haven't had a period in years now because the miracle of birth control pill for me. Um, but it's shelves upon shelves of different brands, different absorbency, different materials. I mean, the branding, the variety really is something else.

**EAU:** the sense

**EW:** The.

**EAU:** I cannot.

**EW:** I mean, I cannot, yeah. And the landscape in the 19, the late 1970s when toxic shock began popping up was roughly similar to this. So why then? Like what was happening in the late 1970s that led to suddenly this syndrome being recognized on a nation, on a, on a national scale?

**EAU:** Tell me, Erin.

**EW:** Okay, here's where we have to get into some tampon nuance.

**EAU:** Yes.

**EW:** In the decades since the first commercially available tampon in 1936, which is Tampas tampon technology had undergone some pretty big changes very gradually at first, since the demand for tampons remained pretty low until the 1960s. I mean, well, you couldn't advertise easily. So word of mouth was the main way that people learned about them. And then there was a great deal of hand wringing over how tampons were a threat to young women's purity and like it's gonna ruin them, right? But eventually though the benefits that tampons provided, like being able to swim or dance, or go on, you know, be in work long shifts, all of these things won out over these anxieties. And by the 1960s, tampons were seen as a symbol of bodily freedom of women's liberation. And as the consumer base for tampons grew, so did the companies making them and slightly different versions of tampons appeared on the shelves, like each of them trying to edge out the competition, right? Like they each have, oh, this one's slightly different. This one has a better name. This one is a better catchphrase. This one is more observant. This one is whatever. All these different things. The applicator the first tampons made were 100% cotton, but these newer tampons began to incorporate other fibers to increase absorbency, [00:50:00] including synthetic fibers and materials developed in the mid 20th century. Things like polyester visco rayon, which is derived from wood, cellulose and processed

with other chemicals. Polyacrylic, which you can also find as an absorbent in disposable baby diapers.

**EAU:** Okay. That makes sense.

**EW:** Carboxy methylcellulose, which comes from plant cellulose and shifts from powder to gel when introduced to liquids and. Even today, it's next to impossible to find tampons made of 100% cotton alone. Like very, very, very few do use those or do you use just cotton proctor and gamble's rely tampon, which took, I know you, I know you

**EAU:** I can't wait to hear all about Rely.

**EW:** this. is the tampon that took center stage in the toxic shock syndrome crisis of the 1980s. Rely was composed of quote, a polyester sheath, compressed polyurethane, foam cubes and carboxy Methylcellulose end quote. And I just wanna like make a point here to say that just because chemical names of things are long and like sound complicated does not mean that they're inherently bad. Um, but. The issue, and then I'll get into this a little bit more, is just like the testing of this, right. Like, because I feel very much like, oh, well those don't sound like natural words. And it's like, that doesn't

**EAU:** Yeah, and it's also like just because something is so-called natural or is cotton rather than rayon, does also not mean that it is safer for you. So something, being a synthetic fiber does not make it inherently less or inherently more dangerous

**EW:** the board. I mean, maybe, maybe research will show that. It, it

**EAU:** Right. But

**EW:** will show that it does not, but yeah. Yeah. We just, the sweeping generalizations I think and just like the idea that like, oh, that has a lot of big words. Yes. Um, that being said,

**EAU:** Okay. Yeah. Let, but let's keep

**EW:** a big, yeah, a big part of this. So, uh, rely was considered and advertised as a super absorbent tampon with lightweight materials able to hold 52, 1500 times their weight in water.

**EAU:** Wow. Sounds like it'll dry you out real good.

**EW:** Oh, well it, yeah, it did to,

**EAU:** that's a problem. Your vagina's supposed to be moist.

**EW:** Mm-hmm.

**EAU:** Anyways, keep

**EW:** Anyways, so with all of these new tampons coming onto the market, coming onto the grocery store shelves in the late 1970s, what was that approval process like?

**EAU:** Tell me

**EW:** To be honest, close to non-existent.

**EAU:** I knew it.

**EW:** mean, yeah. Until 1976, tampons and sanitary pads were classified as cosmetics.

**EAU:** Wow.

**EW:** Which, and so they were technically under the jurisdiction of the FDA, but there really wasn't any formalized review process for devices like those that were worn or implanted in the body or used to diagnose diseases. No official approval for these was necessary.

**EAU:** Yeah,

**EW:** mean, and this, this is a case I think of like technology moving faster than our ability to like understand the implications of it.

**EAU:** Yeah. Yeah.

**EW:** And over the 1970s, it became apparent that like, we need to do a better job. This was a mistake to not have any sort of official approval. Serious issues with pacemakers. IUDs like the Dalkon Shield, lens implants and other medical devices had left people with severe injuries and pursuing lawsuits. So in 1976, the medical device amendments was added to the federal drug, the Federal Food, drug and Cosmetic act. And it's worth getting a bit into the nitty gritty

here because of the bearing that this would have on the emerging issue of toxic shock syndrome. So under this amendment, devices were put into one of three categories based on their perceived risk. Class. One was almost no risk, like bedpan, nitrile, examination gloves, that sort of thing. Class two devices carried a bit more potential for risk, so like tampons and hearing aids, and required more testing, labeling and monitoring. And then there was class three. This was the riskiest bunch, like artificial hearts or other experimental devices. But when this amendment was introduced, what do you do about the existing devices like tampons? Right? Most of these pre amendment devices were just grandfathered into the system, and no disruption to sales or production happened. Any new tampons I'm talking about. Tampons specifically here could be ushered, uh, through this approval process pretty quickly. If the company could demonstrate that they were, quote, unquote, substantially equivalent to pre amendment devices,

**EAU:** a problem.

**EW:** it is a problem. And one of these substantially equivalent [00:55:00] tampons was Procter and Gamble's Rely tampon

**EAU:** Okay.

**EW:** Rely, it even absorbs the worry. This was the tagline on the sample box containing four rely tampons that was shipped out in mass across the US to millions of homes from the mid 1970s to 1980. It's just as like you get free tampons in the mail, try it out. Maybe you like this super absorbent.

**EAU:** huh.

**EW:** The materials that were used in rely tampons had been used in other tampons on the market, just not the precise configuration. But how could anyone know that

**EAU:** You cannot.

**EW:** manufacturers are not required to disclose the exact composition of tampons, like materials, fragrances, et cetera, because it qualifies as a trade secret.

**EAU:** Y, the trade secret.

**EW:** secrets, I mean, I have a lot of thoughts on that in some recent news about certain quote unquote un extinct animals. Anyway.

**EAU:** Oh my gosh.

**EW:** We should do an episode. Okay. "Dire Wolves". I mean, I, I can't say it without using quotes because, anyway, overall, back to toxic shock. Um, as far as I could tell, until the late 1970s, though tampons had not been associated with any significant health issues or outbreaks since they had hit the shelves decades before. Like, there, it really doesn't seem to be like something, it was like more maybe very, um, sporadic types of in, you know, individual issues, not outbreaks. So the spate of toxic shock syndrome cases, uh, with the beginning in the late 1970s would reconfigure the perception of these devices as inert and completely benign. What had changed? That was the question that the CDC sought to answer. The June 27th, 1980 MMWR described the link between toxic shock and tampons. Of the 105 cases since September, 1978, 96% occurred in women aged 12 to 52. During their menstrual periods, 96% and the case fatality rate was 15%.

**EAU:** See, that's so

**EW:** It's so high. That's when I was asking, and you were like, well, it's pretty low, like 15% is very high.

**EAU:** So, and, and that's why I said I don't know all the numbers I saw. I think were from current data.

**EW:** right, right.

**EAU:** So Yeah, grains of salt.

**EW:** exactly. Yeah. In one case control study where they matched someone who had toxic shock with another person who didn't like similar age, socioeconomic status, geographic location, et cetera, they found that 100% of the cases used tampons compared to 86% of the controls.

**EAU:** Mm.

**EW:** Vaginal cultures of those with toxic shock. Before starting antibiotics showed 94% positivity rate for staph aureus and no similar cultures had been done for controls because like it you could,

**EAU:** Retrospective.

**EW:** Right. But in general, the prevalence of the bacterium in the vagina and cervix ranges from two to 15% is what I saw in this, in this book.

**EAU:** Yeah. And well, and because it depends too on, it can be up to 40% when it's just staph aureus, but not all of them are gonna produce the toxins.

**EW:** right, right, right. Yeah. Follow-up studies sought to get a handle on which tampons and why, and what they found is that across the board, tampons with higher absorbency were associated with toxic shock syndrome. Several brands were implicated, but the clear winner, um, if you could call it that, I guess, was rely with 71% of those who had contracted toxic shock using the brand.

**EAU:** Wow. I didn't realize it was that

**EW:** 71. Well, and it's hard to say how much of it was relies popularity because it had become very popular over a very short time. Especially with all those mail out, you know,

**EAU:** Mail out things. Yeah. Like what percentage of those 86% of people who didn't get toxic shock also were using rely tampons.

**EW:** of those in the control group use the brand. yeah. yeah. But it wasn't just down to relies popularity. Right. The risk seemed to be higher for that specific tampon compared to other tampon brands and researchers suspected that it had something to do with the composition of the tampon itself. So like I mentioned, all of the individual components of the relied tampon had been used in other tampons previously, but not in combination. And there seemed to be something specific about the blend of polyester and carboxy Methylcellulose that encouraged bacterial growth. As you can imagine, this was not welcome news to Proctor and Gamble who were busy conducting their own studies that naturally were intended to cast doubt on what the CDC had found. They even tried to strong arm the CDC into giving them the names and contact information of the women who had been included in the first [01:00:00] study.

**EAU:** excuse me.

**EW:** Yeah. 'cause they were like, the, the CDC is inflating cases of toxic shock. Like, we don't think that these women actually had toxic shock, so we're gonna have to go to their doctors and look in their medical records.

**EAU:** not.

**EW:** The CDC was like, I'm sorry, what? No, no. So instead the Proctor and Gamble tracked down women who had called the company and complained that the tampons had made them sick, which like, there were a lot of complaints about, relies specifically their intention with tracking these women down was to try to undermine the CDC study saying that the cases of toxic shock they included weren't really toxic shock. And so rely has, you know, nothing going on. Uh, this didn't work. And in response. Then they were like, well, we'll try something else. They were like, let's do this, this contradictory PR approach where they touted rely as, you know, these outstanding tampons, super unique and they give you what no other tampon does. Also at the same time, by being like, but like rely is just another tampon. It's not any different than these other tampons. Not any more dangerous than the other tampons out there. So it's like they're saying

**EAU:** We are the best. We're so different. We're just like everyone else.

**EW:** everyone else. Exactly. Exactly. But at a certain point they realized that there was nothing that could be done, and the CDC data was pretty damning. And so in September, 1980, they realized the inevitable and they tried to get ahead of like the bad PR storm, and so they voluntarily pulled, rely from the shelves and issued a recall.

**EAU:** I don't think I realized that it was a voluntary, so they did, they didn't actually get banned.

**EW:** No, it was a voluntary, recall and this included like print and television campaigns. And there's, I think that like there's more to that story in terms of like, I think that they saw the writing on the wall.

**EAU:** Well, totally. But I just like thought that they also actually got banned.

**EW:** No.

**EAU:** Okay, cool.

**EW:** Well, and then the, yeah, because this, there were implications to this, right? Because on the one hand, this is great, this is what needed to happen, rely, there was a clear association with rely specifically and toxic shock syndrome. So this meant that this, you know, potentially dangerous product was no longer going to be available, available for purchase. But on the other hand,

this focus on rely tampons only provided a sa, a false sense of security once they were removed from the shelves. And it obscured the nuance in the relationship between tampons and toxic shock syndrome.

**EAU:** Yes.

**EW:** It is hard to overstate the media frenzy surrounding toxic shock syndrome. In 1980, it was the third leading news story in the nation behind only the Iranian hostage situation and the presidential election

**EAU:** wow.

**EW:** Toxic shock. The next, it was everywhere, and this was overall, like we talked about, a good, a good thing in terms of raising awareness. The CDC estimated that tampon use dropped from 70% to 55% by the end of 1980 because of toxic shock

**EAU:** Wow.

**EW:** but because the research was so new, misinformation was everywhere With journalists and news anchors reporting all kinds of unsubstantiated hypotheses about the nature of this infection. Things like rely tampons, cause toxic shock syndrome, period. That's it. Toxic shock syndrome is a variant of scarlet fever. Tampons cause abrasions or ulcerations that serve as a root of entry for the bacterium Tampons Act as a plug that allows for bacterial growth. Leaving tampons in too long, causes toxic shock. Removing tampons too soon causes toxic shock. I mean like just so many there, there was no clear, coherent message. And part of it is like we discussed because it is a very nuanced thing. Um, but I think another part is because there was such fear and anxiety about like we need to solve this and so we need to report this as like we need to have a clear message to get out to the public. Rely tampons caused toxic shock.

**EAU:** That's the, that's the message

**EW:** That's the message. Or tampons cause toxic shock or taking them out too soon. You know, like all of these different things. And then you have some older male news anchors that refuse to say the words tampon or menstrual cycle on the air.

**EAU:** So what did they say?

**EW:** They just didn't report on it or they made somebody else do it. Yeah, yeah. But the rest of them ran with the story. The mixed messaging and extensive airtime given to guesswork both contributed to the fears that surrounding toxic shock syndrome. I'm surprised I haven't stumbled more over

**EAU:** Oh, you've been doing great.

**EW:** thing to say over and

**EAU:** TSS, you could say,

**EW:** I might, maybe I'll switch to that, but in it, but, but also so you're contributing to the fears and then [01:05:00] also shifting blame to the consumer.

**EAU:** Right. That's the thing. That's the thing. I think Erin, and I think that that still happens today, even in the talk of like, well, did, are you using the right

**EW:** Are you using the

**EAU:** leave it in too long? Blah, blah, blah. And I'm like, did you not. Buy the organic ones?

**EW:** right.

**EAU:** I'm sorry. What?

**EW:** Yeah. Because the, that's the thing is that the removal of re rely tampons didn't mean the removal of the threat of toxic shock syndrome. And in fact, one report found that between January and September of 1980, which is when re rely was still on the market, 50 cases of TSS were reported in Minnesota, 45% associated with rely. So it's 50 cases between that, those months and in a similar period of time after rely had been pulled, there were 59 cases mostly associated with other super absorbent tampon

**EAU:** Mm-hmm.

**EW:** But now that there was no single brand to blame,

**EAU:** No scapegoat.

**EW:** No scapegoat. The responsibility to prevent the condition felt entirely to the consumer with the logic following that if someone developed TSS, it was because they weren't using tampons properly.

**EAU:** You didn't read the instructions

**EW:** and on top of finally standardizing what Junior Regular Super and Super Plus actually meant, which happened in 1989.

**EAU:** Erin, I wanna do a whole episode on the tampon task force

**EW:** Oh yes. The Tampon Task force. Yes,

**EAU:** and the angina. I learned so much.

**EW:** I know there is. I just, it seems like there was, um, it took so long to get anything done.

**EAU:** It took so long. Like I it's unfathomable how it took so long and how then even after all that work, people are still like, yeah, we're just gonna use saline still.

**EW:** Yes, I know. I know. I know all of that. Yeah, there's, there is so much there. Um, i'll recommend a book at the end of this, but yeah. But, um, so yeah, it, they had standardized absorbs and then the FDA had also issued guidelines for warnings to be included on the tampon box or in an insert inside the box. But the initial warnings were very vague. Attention tampons are associated with toxic shock syndrome. TSS is a rare but serious disease that may cause death, read and save the enclosed information,

**EAU:** Wow.

**EW:** no detail on symptoms. So like, you're just like, there's this deadly disease, we don't know what it looks like.

**EAU:** Is it from the tampon or is

**EW:** do I look

**EAU:** how do you know if I have it?

**EW:** Yeah, no information on how tampons were associated, even though at that point it had been uncovered through research that it was likely that super absorbent tampons created, like you said, this more aerobic environment for staph aureus to multiply and frequent change in created even more aerobic conditions.

**EAU:** Oh, interesting.

**EW:** what some of the research said, but like you said, there's it's nuance. There's More more factors at play, but even that messaging wasn't simple enough to be reported by major media outlets. And so the issue continued to be one of individual responsibility rather than consumer protection. Women were told to monitor their own bodies for signs of this deadly disease, rather than manufacturers being forced to reevaluate their product and improve it to protect the health of their consumers. If there was an association between whatever component, whatever material, and an increase in aerobic environment or whatever it was, and yet as Shera Ostro, who's the author of Toxic Shock, a Social History Points Out, which is the book that I read for this, things could have been much

**EAU:** Mm-hmm.

**EW:** If the toxic shock public health crisis had happened a year later, which would've been the first of the Reagan presidency, there wouldn't have been nearly as many women in the administration to advocate for women's health. Women like Dr. Catherine Shans, the EIS officer at the CDC, during the time who led the TSS task force that could have led to decreased awareness of slower change to manufacturing guidelines, and even less attention to the lack of transparency about tampon production. Since the height of the toxic shock syndrome crisis in the late 1970s and early 1980s, incidence has declined. Thanks. In large part to, from what I can tell, rely being pulled materials like polyacrylic, polyester foam, and carboxy methylcellulose being discontinued in tampons, absorbency being standardized, and amazing advocacy and awareness work. Updated labeling requirements as of 2017 have boxes prominently display attention. Tampons are associated with toxic shock syndrome. T-S-S-T-S-S is a rare but serious disease that may cause death, read and save. The enclosed information that enclosed information must include [01:10:00] symptoms and estimates of incidents, advises to use minimum absorbency and declares that risk can be avoided altogether by not using tampons and alternating tampons with pads, which is not true

**EAU:** can be avoided altogether.

**EW:** apparently. That is what, that is what I read. Yeah. Yeah, that's What? I read. that the enclosed information has to say.

**EAU:** Okay.

**EW:** Despite the fact that it's been over 45 years since this story broke, there is still confusion I feel about tampons and toxic shock about toxic shock overall at both the scientific and consumer levels. You know how the two are related, how to reduce risk and what safer alternatives exist. Can we make them, do they exist given that more than 10% of women in the US are menstruating at any given time?

**EAU:** Oh, I love that statistic.

**EW:** This is not okay that these, that we don't know the answers to

**EAU:** yeah,

**EW:** research into women's reproductive health is continually underfunded and deprioritized. And the shame that surrounded, that surrounds menstruation keeps many women from talking about these issues or feeling like they're justified in demanding that things change. So, Erin, tell me, are things changing? Do we know more stuff now?

**EAU:** I am not gonna be able to answer that question really, but I can tell you about what we do know.

**EW:** I love it.

**EAU:** Okay. Right after this break.

**EAU:** So. Let's just talk numbers for a quick second. Uh, this is so toxic. Shock syndrome. Staphylococcal and non staphylococcal, um, is a reportable disease in the US and that's how they're classified staphylococcal, non staphylococcal toxic shock. Um, since 1983, uh, staphylococcal, toxic shock has been notifiable and since 1995, streptococcal toxic shock or non staphylococcal has been notifiable. Global numbers pretty much impossible for me to find. Um, I don't have them, but this is, both of these diseases are quite rare and the numbers in terms of the prevalence or the, the incidents each year, um, really, really, really vary depending on what paper that I read. Um, most of them seem to come to the conclusion of around one-ish case per 100,000 people per year. But, but when I say they vary, I mean like there was a paper from 2018 that used UK

Biobank data and in Europe and the uk these are not notifiable diseases. Um, so the data is even more sparse. But looking at like biobank data, they estimated an incidence of 0.07 cases of toxic shock per 100,000, which is really, really, really low.

**EW:** Huh?

**EAU:** Um. Most of the US data estimates between 0.5 and one per 100,000. Though I've seen some that say up to two per 100,000 cases per year.

**EW:** Hmm.

**EAU:** Um, when it comes to streptococcal, 'cause most of that is for staphylococcal toxic shock, it's even more all over the place in terms of like what the numbers are, the estimates are. But it is estimated that some, somewhere in the range of like 10 to 20% of people who have an invasive group, a strep infection will go on to develop toxic shock. And so estimates also range between like one and five per 100,000. Um, but you'll be happy to know that because I was unsatisfied with all of the numbers that I was finding and because. We're not gonna, we're not quite Erin. Yes, we're Erin Math thing. Okay.

**EW:** Erin ish Math.

**EAU:** Erin-ish math. Um, I went, this is a notifiable disease in the US so if you didn't know this, you can go directly to the CDC where they have a national notifiable disease survey and they have an interactive tool that can tell you that from, I know, me too. From 2016 to 2022, that's the most recent, uh, timeframe that they had. There were 2,144 cases of streptococcal toxic shock and 217 cases of non streptococcal or staphylococcal toxic shock that were reported.

**EW:** interesting the, the difference between in magnitude between the

**EAU:** Right. Streptococcal, I mean, streptococcal infections are like. Quite still rampant. And so if 10 to 20% of them are developing toxic shock, so if we look, then if we err in math that a little bit, um, there's a range in years, but 145 to 416 cases per year was the range for streptococcal toxic shock in those different years. And then between 15 and 44 cases per year of staphylococcal toxic shock in the whole entire us, that's what gets reported. And this is a reportable disease. So these numbers should be accurate in terms of what is identified. [01:15:00] And so this is where we then have to remember that the. Click, like the case definitions that we use to identify these cases are imperfect, right? And so these

are probably underestimates, even though they are accurate reported numbers, right? Because these CDC criteria, and they do say this on the CDC website, they're like, you shouldn't use this as a clinical diagnosis. Like this isn't what you should be using at the bedside to decide am I calling this TSS or not? Because this is what we're using from a research perspective. And that's a little different, right?

**EW:** Interesting. Should they be different?

**EAU:** I mean, they have to be in part because of this, the fact that like the probable case definition, like you can't, you can't do a full case definition without the one to two weeks later having this sloughing rash. You're not gonna have that in the setting of, right. Um. So, yeah, so there, there is a little bit of variability there. Um, and so these criteria will, will likely inevitably result in some degree of underreporting because of that, um, a lot of people are likely lost to follow up. And so you might not get the records on did they end up developing a rash. Can we confirm that that's what that was or not, right? Like, don't get me started on our lack of centralized medical records. So how can you go back and find that information? It's hard. Um, yeah, so we, the, it is, the good news is overall it is very, very rare. Both staphylococcal, especially staphylococcal toxic shock as well as streptococcal toxic shock are both rare diseases likely under reported, but still very rare. And we talked already about the kind of mortality rates and things like that. Those haven't changed from the data that I found in recent years, at least. Um. When it comes to the questions that you asked Erin about, like, where are we going from here? What else have we learned?

**EW:** what's good? What change, what change has happened?

**EAU:** I don't know, Erin, if we've come up with any changes since the tampon task force of the 1980s. Isn't that depressing?

**EW:** It is. It is.

**EAU:** It is. So depressing. And I, I, yeah, I, so I don't have any, I don't have any new news. Um, in terms of what do we know about tampons and these relationships besides what we've talked about already? Uh, all of the. Across the board the recommendations from CDC, from FDA, like based on all the epidemiological evidence that we have, and it's all epidemiological. And then there's some, you know, studies that have looked at like the composition of this tampon versus that tampon. Is there a difference in lab settings of how much bacteria that you can grow and that kind of a thing

**EW:** Yeah.

**EAU:** which are

**EW:** like does, right, does that translate to human?

**EAU:** exactly. Uh, and like who, who's funding those studies? I don't know. Um. Most of what I saw did not suggest huge differences between the tampons that exist today, the tampons that are on the market today, regardless of their composition in just in a laboratory setting, how much bacteria are they growing? Right. Which again, points to that. It's not, it's not just the tampons themselves, it's this interaction between the tampons and the environment. The recommendations across the board are to use, like you said, the lowest absorbency that you can, which at least now they're standardized

**EW:** I mean, I guess,

**EAU:** to some

**EW:** still, how the heck do you like, yeah, yeah.

**EAU:** Well also, because I always think, I used to think about this a lot when I used to use tampons, um, like what is six grams of menstrual blood? I don't know.

**EW:** No idea.

**EAU:** No clue

**EW:** It's just a little blue liquid, like

**EAU:** Oh, yes, that's what it is. That's what it looks like, so, yeah. But that, that is the recommendation to change them at least every six to eight hours and not go longer than that. I didn't know that you weren't supposed to use them overnight growing up all the time. Did,

**EW:** Yeah.

**EAU:** but I mean, again, because this is so rare, like I, I really like Erin, the way that you went through all of the history of this and kind of emphasize the fact

that like, we need to hold accountable the correct groups. Right. And it is not an individual's job to make sure that they don't get it.

**EW:** It's, and like at, at the very least, I think that what it shows is just, and I know that there are people working on this, and I'm not saying that there's no one working on this, that there's no effort being, you know, no interest, no effort, no awareness, but like the fact that we don't have some of tools maybe to be like, who is likely who has antibodies at high enough levels? What are the screening protocols? Like, how can we

**EAU:** How can we do

**EW:** [01:20:00] Yes. How can we do better?

**EAU:** Yes. Yeah. And I, and I do think that that's an interesting arena is like, and it's hard because of how rare it is, right? So like, where's the funding for it? 'cause people don't care as much. Where is the like, high kind of clinical suspicion to think, is there a test that, do I have a test that I can run? How do I run that test on what population should I be running that test? When should I be thinking about it, when should I not? And those kinds of things. So it's all like, there needs to be a lot more done. Um, I, I didn't find any updates on it and maybe I missed it. So if you know of things, please let us

**EW:** Reach out. Yeah.

**EAU:** But if you wanna know more, woo, do we have papers and sources for you?

**EW:** Yeah, we do. I have some papers, but I would say again, I'm just gonna shout out that book, uh, toxic Shocks, toxic Shock, A Social History by Shara Vostro.

**EAU:** Love it.

**EW:** It's great.

**EAU:** I had so many papers for this, Erin, um, let me tell you some of my favorite ones. Okay. Uh, from The Lancet 2019, or sorry, the Lancet Infectious Diseases 2019 by Burger et al. There was menstrual toxic shock syndrome case report and systematic review of the literature. Such an interesting case report in there too. Um, really highlights how much we don't know and how we likely under diagnose it. Um, there was a really very thick book that I read, just one

chapter of called The Paul Grave Handbook of Critical Menstruation Studies. Uh, and the chapter was called Toxic Shock Syndrome and Tampons, the Birth of a Movement and a Research Agenda. So that was an interesting, uh, really liked it. But I also wanna shout, I had a bunch more like, you know, research papers and things, but I also wanted to give a shout out to a Washington Post article from 2016, um, by someone's last name was Cowart. 'cause I didn't write their first name. That was called Women are Still Getting Toxic Shock Syndrome and no one quite knows why. Um. It just is a really, it's kind of like this podcast, but in written form. It was a really great overview. They went into the history, they went into like way more detail on the biology than I see in a lot of, uh, you know, non, yeah. So it was a really great, like, very overview of it. So I wanted to give that one a shout out. But we have so many more sources on our website. This podcast will kill you.com, all of them from this episode and every one of our episodes.

**EW:** Thank you so much again to Autumn for sharing your story with us. We, we appreciate it. Just more than we can say.

**EAU:** it really does mean so much to us. So thank you. Thank you also to Blood Mobile who provides the music for this episode and every single one of our episodes.

**EW:** Thank you to Tom and Lianna and Pete and Brent and everyone else who Aact, right. Who does so much, um, to help us with this podcast.

**EAU:** really love it. It's fun. Thank you to you for listening and watching.

**EW:** Yeah.

**EAU:** Uh, I'm embarrassed by that face. We really like,

**EW:** It was, I liked it. I liked it.

**EAU:** thank you so much for, for being with us through this. I hope you liked this episode.

**EW:** Yeah. Yeah, let us know. Uh, let us know what else you wanna hear, and as always, a special thank you to our patrons. We appreciate your support so very

**EAU:** Yes. Thank you.

**EW:** Well, until next time, wash your hands.

**EAU:** filthy animals.