



Pill Pop

Transcript for episode 1 –
Moses Supposes He Has a Diagnosis

Silvi Vann-Wall: *Pill Pop*. A road trip for the chronically ill...

Izzie Austin: It's also a podcast!

Pill Pop is recorded on the lands of the Wurundjeri people, and we wish to acknowledge them as Traditional Owners. We would also like to pay our respects to their Elders, past, present and emerging.

Silvi: We'd also like to give a content warning: this podcast contains detailed discussions of illness both physical and mental, and while we take a funny tone, this content may distress some listeners. In Australia, Lifeline is free to call on 13 11 14, and we'll have a list of local and international support services on our website, wheelercentre.com/pillpop.

Izzie: Right-o, off we pop...

Silvi: I see what you did there.

[fade to music sting – main theme]

Both: Last time!

Silvi: Hey, we should christen this ambulance. What's a good ambulance name?

Izzie: Ambu-Lance Armstrong?

Silvi: Terrible. I love it.

Both: Coming up!

Cristina Spizzica: I was in the shower and then it just kind of hit me, and I had to get out of the shower and then I just kind of laid down in the empty bath, and I was just in the bath just like crying. And I was like, *this isn't good*.

Silvi: Yawns.

Izzie: Oh, this was a mistake.

Silvi: Oh, what is this?

Izzie: God, we should pitch a tent next time.

Silvi: Yeah. Oh, did you bring the tent?

Izzie: I did. It's – it's in there. It's in one of these cupboards. Ambulances have too many cupboards.

Silvi: Okay. I can see the defibrillator paddles. Actually no. That's ... yeah, I think I slept on them.

Izzie: Do they even still work?

Izzie: Okay, pause. If you've just joined us on this road trip, you may be wondering – what are we doing?

Silvi: Well, we're making a podcast about chronic illness called Pill Pop. It's primarily an interview show and a space for chronically ill people to have frank discussions about their lives.

Izzie: If you're not chronically ill, no worries. We don't discriminate.

Silvi: Yeah! I'm Silvi, by the way, I have ulcerative colitis. It's a disease that causes chronic inflammation of the bowel. Hot!

Izzie: And I'm Izzie, I have Type 1 diabetes. My immune system recognises the insulin producing cells in my pancreas as a threat and kills them on sight.

Silvi: Gnarly. So, right now we're sonically touring the country in a bent up old ambulance to find and talk to people just like us.

Izzie: And discovering the inside of their bodies while we're at it! Like the episodes of *Magic School Bus* that Miss Frizzle didn't want you to know about.

Silvi: We promise that's not as weird as it sounds. But, it could be, if you're into that.

Izzie: Okay, back to the show!

[SFX: music]

Silvi: When I was in hospital all those years ago when I was getting diagnosed I was almost hit with the – with the paddles.

Izzie: Oh wow!

Silvi: As I thought I was going to go into cardiac arrest.

Izzie: Oh my god.

Silvi: And that's because they took a blood test that incorrectly said that my potassium levels were through the roof.

Izzie: Wow.

Silvi: ... much higher than they should have been so, they took that as a sign that I was going to go into cardiac arrest. They wheeled me into the emergency room with the paddles.

Izzie: This is really dramatic.

Silvi: This is an exclusive club.

Izzie: Oh wow, yeah.

Silvi: And basically seconds before they hit me with the electric shock. Oh, I don't think it's an electric shock but it's – that's what I imagine it to be?

Izzie: I think it is though.

Silvi: Well it is. Yeah, kind of.

Izzie: Yeah. Because it's supposed to stop your heart so that it can start up again properly.

Silvi: Right, yeah. Luckily, I never found out because yes they did another blood test. They were like, 'hang on we better check' because for the previous few days my potassium had been too low. And that was the pattern. And so they were like, well hang on, if suddenly it's too high, we will just double check in case our tests are wrong.

Izzie: You hadn't just been pounding the bananas.

Silvi: Yes, but no they did another test and they said okay, well, actually we were wrong. Sorry about that. We'll unhook you and wheel you out. Sorry ma'am.

Izzie: Yikes. That's, um ... yeah. Oh man.

Silvi: Meanwhile my anxiety is through the roof. Yeah.

Izzie: Yeah that's probably not good for your heart too...

Silvi: Yes! You know, a few more seconds, they probably would have had cause to use the paddles anyway.

Silvi: So, why did I choose to buy an ambulance off gumtree and have these reminders of this you know, uh – near fatal experience I had? I don't know.

Izzie: What are our guests going to think when we rock up in an ambulance?

Silvi: I think... they might be a little bit wary. Understandably.

Izzie: They might just think we're incredibly prepared.

Silvi: Yes. Yes, or incredibly insensitive. Mm hmm.

Izzie: Guess which one!

Silvi: I think they'll get it. I think once we introduce the ambulance as our friend –

Both: Ambu-Lance Armstrong.

Silvi: They'll be into it.

[SFX: music]

Silvi: So I'm excited, because we're actually going to visit our first guest today. Yeah.

Izzie: Yeah, it's our friend Cristina.

Silvi: It is our friend Cristina, and she's going to talk to us about something she got diagnosed with quite recently in her adult life, but that's been troubling her for a long time. Something that a lot of uterus-having people might experience and will remain undiagnosed for a lot of them as well.

Izzie: Which is, honestly a terrifying statistic.

Silvi: It is, yeah. There goes my anxiety again, better get the paddles.

Izzie: Oh yeah. Look, there is nothing like having a mystery illness to just give you anxiety about stuff.

Silvi: True, yep.

Izzie: Just, what could this be? My last mystery illness turned out to be diabetes, so let's roll the fucking dice!

Silvi: Umm, Izzie, we've been on the road a really long time. I didn't think Cristina was that far away.

Izzie: Yeah, look I'm – I'm trying to only make left turns. I I slept really weird last night and I I fucked up my neck and now I have to turn my whole body to look to the right. So ...

Silvi Are you serious?

Izzie: Yeah it's not great to be the driver when you're doing this. Yeah, but I will admit we've gone a lot further off course than I thought we would.

Silvi: Yeah.

Izzie: That's my bad. I'm gonna own that.

Silvi: Yeah, yeah. I did feel like we took a wrong turn somewhere.

Izzie: Oh we've taken – we've taken a few. I'm ready to open up to that. I'm sorry. God, where are we?

Silvi: Oh hang on, maybe you should turn here.

[SFX: car noises]

Izzie: Oh, my neck! Okay. Yep, yep. That looks good. Okay.

Silvi: Just keep going. Yep.

[SFX: Rumbling car and crashing into water. Ocean sounds. Ship sounds. A foghorn sounds in the distance. Wood is creaking, sounds of a dining hall, smooth jazz is playing on a piano.]

Cristina: The way I would put it, is: picture you are sailing on a cruise ship. Everything's chugging along pretty nicely. So you keep going a bit more, the waves start to get a little choppier, and you go like, 'Oh you know, that's fine. That's normal.' And then, the sky's starting to get a little bit dark and you're like, 'That's fine. That's how days go. Day becomes night.' And then things are starting to get a little rough and now you're starting to worry and you go, 'Hmm ... I know that this is expected,' but now I'm like, 'is this normal though?' It's starting to rock quite a bit. But then all of a sudden everything just kind of stops ...

[all music and sound effects stop]

Cristina: ... and at this point it's also become pitch black ... and then you hear, kind of in the distance, what sounds like a foghorn. And you're like, 'Okay. Does that mean – are we in danger? Is something bad happening?' And then the foghorn slowly starts to get louder and louder. You still can't see anything and you're looking around for a lighthouse but there's nothing there, all you can hear is this horn and it's

getting louder, and louder, and louder, so loud that it's vibrations are kind of shaking the whole ship and you're starting to freak out. You're like, 'Am I about to hit something? Am I okay? I still can't see anything. I'm panicking.' You're – the ship is starting to sway. The waves have come back and all you can hear is this loud, loud sound that just won't go away. And eventually all you can do – it's knocked you to the ground, and – all you can do is just kind of cower there in the foetal position with your hands over your ears, just hoping that you won't hit anything. And it's this deafening sound, and eventually either you do hit something, or the seas calm down and night becomes day, and everything was fine. But I guess that's how I would describe it. It's like this kind of foghorn.

Cristina: Hi. My name's Cristina. I work in marketing, I do a lot of improv comedy, and I have endometriosis.

[SFX: music, main theme]

Cristina: The basic gist of endo is that ... So when you're on your period, the lining of your uterus breaks down and gets ... and comes out of you. And that's what the blood is. That's the lining of your uterus. For people who have endometriosis the lining also somehow comes outside of your uterus, as well as on the inside. And so these bits that are being expelled are somehow getting outside of your uterus and are, becoming kind of adhesions on parts of your reproductive system. And when they're triggered, when the period comes, it's those kind of adhesions that cause the pain and then they kind of cause referred – they can cause referred pain to other areas and so that's essentially what's happening. But there is – and I will get to it – there's no way to know for sure if you have it like kind of on the surface. It can be a very difficult thing to determine if someone actually has endometriosis.

Silvi: Cristina, when did you find out that you had endometriosis?

Cristina: Well it's an interesting question, because there's, I think there's a difference between finding out what you have, and also knowing that there's something that's not right, but also not knowing what it is. And so I think my journey of diagnosis for endometriosis – ooh I like that rhyme – was just ...

Silvi: There's a lot of '–osis'es.

Cristina: A lot of '–osis'es.

Izzie: Moses supposes his toeses are roses...

Cristina: Exactly.

Izzie: But Moses does not have endometriosis, so we don't care.

Cristina: Not that we know of. I distinctly remember, and I was reminded about this when I looked at my Timehop the other day and a tweet popped up from nine years ago ...

Silvi: This is why I disabled that feature. Literally one of my worst nightmares: to see me from nine years ago.

Cristina: Yeah well, I tweeted something to the effect of – in like all caps: 'worst stomach ache ever'. And then there were a couple of replies to it that I saw, to my friends and I'm just and so they like, 'Oh is that your period?' I'm like, 'No it's – it's different. It's like I do have my period but it's a different kind of pain and it's up higher. It's like right underneath my ribs and it's kind of like stabbing me in the stomach', and I was just so, so confused and I feel like that must have been the first time that it happened, because it really took me by surprise, and so yeah that was I guess when I was about yet 17, 18 or so. And I also kind of felt like – it almost felt like there was kind of gas that needed to get out and I just would get this kind of visual of me just taking a knife to my stomach and just kind of slicing it open to just relieve all the pain like in my head I'm like ... not that I actually wanted to do that but I had this visual of like (imitating escaping gas) sssss it's like that ... would for some reason like that would help. I think I'd started Googling at this stage, like, 'bad period pain but not in period area'. Like yeah. Like, 'pain up in intestines'. And then I think in one of my Google searches was one of the first times that the word endometriosis appeared to me and I was like, 'Oh.' And then I'd kind of read all the symptoms and I was like, 'Hmm mm hmm. I think ... I think this might be onto something here.'

And so when I went back to the doctor and kind of put it to her she's like, 'Oh yeah. So what we can do is we can try and put you on the pill and hopefully that will make your periods less bad. And because of that that will make the pain you get from endo less bad.'

I'm just trying to like vaguely remember the timeline in my head. I think I just sucked it up for a couple of years and I'm like, 'Okay I'm just going to deal with this and hope that it kind of solves itself to a degree, or I'll see if I can just put up with it,' because I knew that it would probably involve surgery. And so I think I just kind of was hoping it might just go away. So for a couple of years I just. Every period that came I just braced myself, got scared. Some months weren't that bad. Some months were horrendous. It would sometimes be the point of I couldn't you know I couldn't go anywhere I was just completely debilitated. Lying on the couch in pain, lying in bed in pain. The worst one I remember ... I don't know what caused it, what happened. I was in the shower and then it just kind of hit me, and I had to get out of the shower and then I just kind of laid down in the empty bath, and I was just in the bath just like

crying for like a good half hour just 'cause I could not move, and I was like cool this isn't good. So, it got to a point I think when I was maybe about 22, where I decided that something had to be done about it 'cause I'm like I can't live like this I don't like living in fear particularly like, you know if I have to go away go on holidays I really hate that this is something that can literally take minimum a day out of my life.

Izzie: Yeah.

Cristina: That I – that I don't have any control over and I didn't want it. I didn't like how it dictated my life. So I kind of bit the bullet and I got referred to see a specialist and I got referred to see a specialist who basically what was decided upon was that it needed to be determined whether I actually had endometriosis or not even though I was pretty sure that I did. And unfortunately the ways to find out whether you do are very invasive. So, the first thing I had to get done was an ultrasound and one of the internal ones where they put the fun little road up your vaginal canal. And I remember prior to that I had to drink a lot of water, and I drank a lot of water far too early.

Silvi: That's interesting, normally for invasive procedures you would not drink water, so what was the reason why?

Izzie: I think they ask you to do that like if you're pregnant and getting an ultrasound as well, like the bladder needs to be full. Yeah. So they don't mistake it for something.

Cristina: Yeah. It had to do with the bladder needing to be full so that they could see things.

Silvi: Okay, oh, that's interesting.

Cristina: Yeah. So all I remember about that day is that I left work early, I drank the water too early, I was in that waiting room too early, and I thought I was going to explode. It was the most – it was almost the single most uncomfortable experience of my life, in that waiting room. And obviously then – full bladder lying on that couch, you know, someone's putting something up you and like you ... ooh. But basically nothing came up in that ultrasound which I was told would be expected because there's kind of like minimum two types of endo you can have. You can have the big old cysts that will come up in things like this or you can have small little flecks that they won't show up in an ultrasound but they can also potentially cause even more pain than a big cyst would.

Izzie: Yay.

Cristina: So yeah. The good news is I didn't have any big cysts. The bad news is the ultrasound was inconclusive, wouldn't prove to me if I had anything, which, even though it was still invasive it wasn't the most invasive thing that could have happened so I was hoping that it would show something. It didn't. And what this then meant was I had to actually have surgery to determine whether I had it or not. And then this surgery would just then double as a time for me to have an IUD put in. So that would be kind of like the temporary ... well the only kind of solution to fixing the pain.

So what happened is I got a keyhole surgery. They looked in my tummy area and I got confirmation that I do have endo. They found all these little flecks of it around ... um around that kind of reproductive area, the intestinal area and they, like, in his words he's like, 'I zapped it off,' so I don't know what they do with that. They just go *pew pew pew*.

Izzie: *Pew pew pew pew pew pew pew.*

Cristina: So the way that it works is like if you can get rid of it that's great but it will grow back. So I actually have – this was maybe three, four years ago now that that happened so I don't know, it's probably grown back by now but that's a thing it's like there's no permanent solution to it. Although one of the things that the gynaecologist did tell me was, 'Well, some women find that if they get pregnant it goes away.' And I'm like, 'Hello sir I'm 22. I'm not going to do that.'

Izzie: Yeah, that's ... that's not a great solution.

Silvi: (disgusted) It's incredible.

Cristina: And he knew, he wasn't like an idiot, but it's also just like, don't even, like, dude I'm not gonna get pregnant.

Silvi: At this ... at that point were you starting to grasp the idea of this being a forever thing, or had that already hit you beforehand?

Cristina: I think, after the first six months I was so happy. And then as soon as everything started coming back I was just like, 'God damn it,' like this isn't – this isn't gonna go away. And so I guess that's kind of stuck with me since then. In a weird turn of events since I got the Mirena removed I felt so much better. Like it affected me in a lot of ways like there was the mental ways as well, then physically as well I kind of it gained a bit of weight and I was just feeling generally kind of uncomfortable. So there's always side effects when you're taking any type of hormonal thing there.

Cristina: In the year, kind of, after having it removed I was fine. It's almost like my body did a reset which was bizarre and I was like, 'That's great.' I mean maybe the endo just still hasn't grown back, but definitely in the past I would say a year or so I've started getting some scary periods again.

Silvi: Often when we've got a mystery problem and you know, Google isn't giving us hard answers, we have to go to the doctor and sometimes we have to go multiple times because we may not be believed. Did you find that was what was happening to you? Were there any sort of push backs where you thought there's something else going on here?

Cristina: Well I mean I guess in a way it wasn't taken super seriously, more in the sense of if you think about the timeline. When I first kind of figured it out it was – I was 19, and then I didn't end up getting surgery until I was 23.

Silvi: That's a long time.

Cristina: It's a long time, and knowing the potential effects that endometriosis could have, even though it's something that so many people deal with and it's not necessarily life threatening. You would think that because of all the pain that we go through, doctors might have been more insistent of, 'no you should get this sorted.' Don't just like, 'oh, just try ... try the pill and see what kind of happens.' I don't think that necessarily didn't believe me, but it's also ... I don't know if there was a lot of kind of acknowledgement of how serious it could potentially be. It's just like, 'oh you know the surgery will fix it and like you'll be fine' kind of thing but it felt like there wasn't much consideration for what necessarily has to happen afterwards I don't know. I feel strange about it because like knowing that it's a thing I will have to live with. And that sometimes it's not bad at all and sometimes it is bad. And then, knowing there's not much that can be done about it, it's hard to know whether people are having the appropriate reactions to it.

Izzie: Yeah is it kind of hard to know like, 'Is this normal pain, or is this a pain I should go to the hospital about?'

Cristina: Well it's a thing, that definitely needs to have – and we can talk about this later – way more education about it, with the high proportion of people that this affects, the education would have made the world of difference to me, knowing that you know, one in 10 people with uteruses in this country have to deal with this. So it's like why aren't ... why isn't it something I could learn when I was younger so I didn't have to go through all of this.

Izzie: You know that's so many, many people. Yeah.

Cristina: You know we grew up, I mean like our periods are painful, deal with it. Yeah. So for the longest time I thought, 'Okay, I have painful periods.' But it's like no, periods are painful but that is not a painful period, that's something else.

Silvi: They shouldn't make you want to stab your belly.

Cristina: Yeah. Yes. I would like to also clarify I never actually wanted to do that. It just felt like that's when I wanted to. I was just like that was just like the thing that's like.

Silvi: But at that point, you know that's – that's too far.

Izzie: Yeah like that's if – that's the image that you like of you thinking of yourself like ... Yeah. Like a system of vents.

Cristina: Yeah. I literally did see myself like the system of vents didn't just like, ah *imitates piercing flesh and steam hissing* that'll do it.

Silvi: That's really interesting, because yeah, I find my experience of chronic illness is – has changed the way I view my body and how I relate to it, so it is more like I'm trapped inside it more than like it is me. I don't know, do you guys feel the same way?

Izzie: Yeah, a little bit.

Silvi: Sometimes?

Izzie: It comes and goes, but it's like, it's been – my story's quite different 'cause I was diagnosed quite young so I kind of don't remember what I was like before.

Silvi: Sure.

Izzie: Like I do remember being quite a self-conscious child. And like ... like I remember being five years old and, like, holding in my belly 'cause I thought I looked too fat.

Silvi: Oh no!

Izzie: Like, that is ...

Cristina: Messed up.

Izzie: Yeah, that's some shit. And then diabetes happened and I was like 'oh cool. Everything sucks forever and I live in this!'

Silvi: Oh, yeah it's, um ... Yeah it's weird to think of your body as a vessel that is breaking down.

Izzie: Yeah.

Silvi: While your mind's inside it going, 'What is happening?'

Cristina: Yeah it's kind of strange to be like, 'Why is my body actively trying to hurt me?' I'm just trying to stay alive and have a good time. Stop it please.

Izzie: I was in like a first year communications class at uni and they started getting onto concepts of, like, the self. And like is – what is your 'self', is it separate from the body? Is it like, just, are you a consciousness in a cup? and I'm like, 'Yeah.'

[laughter]

Silvi: Solved!

Izzie: And the tutor's being all, you know, philosophical about stuff and I'm like, 'Nah!'

Cristina: Done!

Izzie: This is me! Wrap it up! Mind-body dualism, I'm all about it.

Cristina: Cracked the case!

[SFX: music, main theme]

Silvi: What is one thing you would say to someone who had just started to suspect that they might have endometriosis? What would you want them to know?

Cristina: I would want them to know that there's a lot of people out there who are going through the same thing, and they definitely shouldn't feel like they can't talk about it, and also don't minimise what you're feeling. And I still do that now, I'm like, 'oh I have endo, but there's other people who have it way worse than me,' and that is the truth, but also: don't minimise what you're going through. If you're in pain, just because it's not as bad as other people's pain, it doesn't minimise your pain so don't feel like it's not bad enough to get checked, or bad enough to talk about or seek treatment about. Your pain is valid.

Silvi: Thanks Cristina.

Cristina: Thank you very much, Silvi and Izzie.

Silvi: So ... you've seen that study where it ranks women with endometriosis by their attractiveness? Have you seen that?

Izzie: No! Oh my god!

Silvi: So yeah, I saw a thing going around on Twitter where a study was done in Italy by scientists? You know, I presume they have some kind of degree between them. It was a study of endometriosis in women and it was ranking the attractiveness ...

Izzie: Ugh!

Silvi: ... of women with endometriosis. Looking at the correlation between female attractiveness and severity of endometriosis.

Izzie: (horrified) ooooooh.

Silvi: And concluding ... that apparently women with endometriosis are perceived as more attractive by the men who are running the test.

Izzie: How did that even get ethics approval?

Silvi: Exactly, how indeed?

Izzie: How did that ... what?

Silvi: And this is a recent study. It's not from ...

Izzie: Multiple people passed off on that!

Silvi: ... 30 years ago. Yes, they did.

Izzie: A lot of people ...

Silvi: Yes, it was peer-reviewed.

Izzie: ... had to okay that!

Silvi: Yeah, they did! And it was – it was looking at things like breast size.

Izzie: (disgusted) Aaaaaaagh.

Silvi: It was super – so – aagh, like I don't have words.

Izzie: Ew!

Silvi: Just noises of disgust.

Izzie: Good god!

Silvi: No. But yeah this is a real thing.

Izzie: And that got ... I wonder what that got funding instead of.

Silvi: Exactly. And what is that doing for people with endometriosis? What – how is that helping them? How is that going towards a potential cure?

Izzie: Yeah.

Silvi: Or better treatment?

Izzie: I imagine they thought it was reassuring. I wouldn't be reassured.

Silvi: Oh god ...

Izzie: No!

Silvi: I've just realised that's – that's probably exactly what they thought they were doing. Oh my God.

Izzie: Good god. So. So okay so if you're in if you're in your gynaecologist's office and they diagnose you with endometriosis and they're like, 'Well, it's incredibly painful it's a lifelong disease. But on the plus side!'

Silvi: Titties.

Izzie: Dem titties!

Silvi: Dem titties.

Izzie: Oh no!

Silvi: And this is, you know, this is why it takes people like Cristina so long to get a real diagnosis.

Izzie: Because – scientists are too busy with this crap.

Silvi: Yeah. Too busy with titties.

Izzie: Too busy with dem titties!

Silvi: It's ridiculous.

Izzie: You know you meet some people who are like the human personification of period cramps.

Silvi: Yes, yes! Exactly. Yes.

[SFX music]

Izzie: Next time!

Charlie Park: You know, I had to think about – what if I want to do something like a yoga class? Do I have to stop in the middle of a yoga class to eat and take tablets? And you know you're not actually supposed to eat, you might know, around a yoga class. They say not to. It's dangerous.

Silvi: For the chakras?

Charlie: Yeah, yep, blows your chakras up.

Silvi: We're talking about medication with Charlie Park.

Izzie: *Pill Pop* is hosted and produced by me, Izzie Austin.

Silvi: And me, Silvi Vann-Wall.

Izzie: And it's produced in partnership with the Wheeler Centre as part of their Signal Boost programme. You can find more episodes on wheelercentre.com/pillpop.

Izzie: You can find us on Twitter @PillPopCast.

Silvi: Editing by Silvi Vann-Wall.

Izzie: With production support and mentorship by Bec Fary .

Silvi: This podcast is recorded at Studio 757 at the University of Melbourne.

Izzie: Music and sound effects are sourced from Audio Network, Soundsnap and Incompetech.

Silvi: And if you haven't already, don't forget to subscribe and leave a review.

Izzie: *Pill Pop* is a podcast about chronic illness. We're not doctors, and no part of our series is intended to be taken as medical advice. If you think something might be up, try to find a doctor you trust. It's a hard journey ... but you're not alone. If anything we talked about today brought up distressing feelings for you, remember that Lifeline is free to call from anywhere in Australia on 13 11 14. And we've got a list of support services on our website, wheelercentre.com/pillpop.

OUTTAKE

Izzie: There's ghosts in your uterus. Do some cocaine about it.

Visit wheelercentre.com/pillpop to listen to this episode – or for more information, including support services. Pill Pop is produced, hosted and edited by Silvi Vann-Wall (she/her) and Izzie Austin (they/them) in partnership with the Wheeler Centre's [Signal Boost](#) programme.