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Stillbirth Happens – let's talk

E02: What happens at the hospital?
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JAIME: Hello, and thank you for joining us on Stillbirth Happens - let's talk. It's a new podcast brought to you by BC Women's Hospital. I'm Jaime.

ERIN BOHN: And I'm Erin. We are both moms who have given birth to stillborn babies. We often say that babies who are born still are *still born*. It's important to talk about our babies as a way to honour them and to help others get through the day-to-day challenges of life after a stillbirth.

JAIME: You may be a bereaved parent, a family member, a friend, or a caregiver. Whoever you are, stillbirth has touched your life in some way. Sharing our lived experiences is important because our unique stories bring common lessons.

ERIN BOHN: We're here to listen to stories about stillbirth from people who know firsthand what it takes and what it gives.

JAIME: So, welcome. We want you to know this is a safe space to grieve, learn, and hopefully gain some understanding and hope that will help you as you go forward with your days.

ERIN BOHN: Part of dealing with the diagnosis of demise is what happens at the hospital.

JAIME: From practical questions about the hospital process to questions about what happens immediately after your baby is born to hard decisions like what to do with your baby's body.

ERIN BOHN: In this episode, you will hear how one parent's stillbirth experience impacted their grief journey. We'll also hear from a registered midwife on how care providers can support families through stillbirth.

JAIME: Erin Sowerby Greene is many things, but Mama to Briar, born still October 20th, 2022 at 37 weeks and 4 days is the identity closest to her heart. Since Briar's stillbirth, Erin

and her partner Cameron, have been working to de-stigmatize reproductive loss and advocate for better support to those with lived experience of stillbirth.

ERIN BOHN: Erin, thank you so much for taking time outta your day to join us on this podcast.

ERIN SOWERBY GREENE: Thank you.

ERIN BOHN: I know Briar's birth story is unique; will you share her story with us?

ERIN SOWERBY GREENE: It's complex. We were so supported in so many ways and let down in so many other ways.

> Our pregnancy was unremarkable all the way through. But, at 35 weeks I developed mild itching that I noticed at the end of the day after a hot bath on my palms and the soles of my feet. I had that probably four or five nights, and then at 36-ish weeks, I had an appointment with my primary care provider and I mentioned these symptoms even though they had resolved, just because they were out of the blue.
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> This was my first pregnancy, so so much of the pregnancy experience is new and novel and uncomfortable that I wasn't sure if it was of any significance, and I'm grateful that that care provider recognized that it being isolated to hands and feet. And no visible rash are pretty telltale signs of the condition called intra hepatic cholestasis of pregnancy, also known as ICP or just cholestasis. That's a liver disease of pregnancy.
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> So they had me immediately tested. I had some blood work drawn. This disease is poorly understood. Each country, each region has their own standards.
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> So my test was done fasted because a lot of liver tests are done fasted. My blood work came back with my bile acids were level 11, which was just barely considered cholestatic. However, with the itching, I had elevated liver enzymes, it was enough to consider myself a patient of ICP.
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> Because my levels were so low they figured that, uh, a wait and see was the best option. The following week, I had blood work done and just by chance it was done unfasted. So my blood work was drawn Tuesday. We had an NST done. Everything was fine.
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> On Wednesday, I borrowed a friend's Doppler to listen to our little girl's heartbeat. She didn't have a name at that time. And then, uh, we could feel and see her kicking out when I had my nightly lukewarm bath at 10:00 PM.
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> We had an appointment at 9:30am with our care provider, just routine appointment. At that point, we were 37 weeks, four days. A minute or two later we went to put the Doppler on to listen to Briar and immediately they couldn't find anything and they started searching all over my abdomen to try to find her heartbeat. And the care

provider, my husband noticed because they put their hand on my leg, and that's when he knew something was wrong.

We were sent off to the perinatal unit at the hospital where they hooked us up to the monitors and couldn't find a heartbeat. Then we got moved into our own room and I think I was still in shock at that point. And, uh, the OB that was on shift eventually came in and told us, “I'm sorry, there's no heartbeat”.

[music fade in]

ERIN SOWERBY GREENE: I don't think anyone's ever ready to hear something like that. We had been so cautious along our pregnancy. We didn't announce to anyone until we hit 20 weeks because my husband and I, we’re both in science - I'm a biologist, he's an engineer. We know the stats. We know we're not above them, but we are at 37 and four! We just felt so close to the finish line. We didn't know how someone could be telling us that, or we weren't gonna cross it with our little girl.

So at that point, I think it would've been appropriate to have, I don't know, a social worker—someone--come in to start talking us through the emotional side of it. Unfortunately we launched right into, with the OB, like asking us “What do you wanna do: a c-section and or a vaginal birth?” And I thought that it would help my body process it to, to try to deliver vaginally.

We were given the cervical dilator, and sent home with sleeping pills, some pamphlets, and told to come back the next day. My body was ready, but within 15 minutes of arriving home, I was having contractions. One minute apart, one minute duration. We got a hold of our care provider and asked what we were supposed to do, and we were advised to come back to the maternity unit.

[music fade in]

ERIN SOWERBY GREENE: It was chaos. It was absolute chaos. It took five different attempts to try to get an IV in my arm. In between contractions, I immediately requested an epidural because I figured with the mental pain I was going through, I didn't need to put my body through that. Although I respect anyone, that could handle both.

So they ran lab work for me and it took, I think it was three and a half or four hours to get an epidural. Meanwhile, I was vomiting from whatever drugs I'd had from the pain, and they eventually got a line in.

ERIN BOHN: And Erin, it's, it sounds like everything went so quickly from the time that you found out. That, there's really not enough time to sit there and think about the new reality of what's gonna happen, and the questions and the choices and the answers you need to provide.

ERIN SOWERBY GREENE: It was wild. It was absolute chaos.

[music fade in]

ERIN SOWERBY GREENE: My partner was, oh, he was so incredible. He was there the whole time. Wouldn't leave my side. And yeah, so I laboured for I think around 10 hours, and our daughter was born at 10:41. She was eight pounds, three ounces. Absolutely beautiful.

We had incredible nurses who helped walk us through choices that we never would've expected to make. There was a student who was present, who was incredible. They had obviously never dealt with a loss like this before, but they saw us as hurting parents and hurting people and just put whatever they were feeling aside and were able to show up for us, and I'm so grateful for them as well.

We were offered a photographer. The hospital has a list of photographers and we were on the fence that we thought it was weird to photograph a corpse and why would you wanna do that? We are so grateful for the nurse who told us that no parent has regretted getting the photos. We're so grateful that she helped us make that decision.

ERIN BOHN: It’s so amazing that you had a nurse that was by your side and walked you through, but she really gave you and your partner the power to make your own choices.

ERIN SOWERBY GREENE: Part of my birth plan had been I wanted to help deliver my baby and do skin to skin immediately, and that this same nurse could notice that I was uncomfortable with that, and she helped me rationalize it and let me know that because my baby is being born still that she won't have the same tone that a live baby would have, and that it doesn't make me less of a mother or less of a, a loving parent, to not hold her immediately.

JAIME: How about further experience in the hospital and and others who were your care providers? Can you share about that?

ERIN SOWERBY GREENE: Yeah, so the nurses were stars of the night and they were amazing. And to keep that momentum going, we've provided feedback to let them know just how valuable that was so that they continue doing things like that because there were a lot of thoughts along the way that where we were let down and if we didn't have these rays of of light, I think we'd be in a lot darker place.

The Erin that you two are talking to today is a whole new Erin. I've been a people pleaser and a doormat my whole life, and Briar has taught me that standing up for what you believe in and what is right doesn't mean that you are a bad person or that you're just trying to cause trouble. My goal now is to constantly push the envelope and advocate for change.

So for three weeks we sat and waited while an autopsy report existed that we didn't know about. I'm in the process of providing feedback to the the hospital as well. In the early days of loss you're barely remembering to drink water or brush your teeth or pull yourself out of bed. So having to advocate for yourself and push for appointments and

try to find these reports. I don't know how we were able to do that, but I'm very grateful that we were.

ERIN BOHN: I remember having to use sticky notes around my house to remember like, eat...you shouldn't have had to advocate so hard. Can I just go back a little bit while you're still in the hospital after the delivery, can you tell me your immediate postpartum experience, like what things were offered to you?

ERIN SOWERBY GREENE: We were offered, um, Benny Boxes. It's a bereavement box from another family who donates 'em to the hospital. They include a hand and footprint kit, which our nurse who delivered Briar, as well as the student that got hand and footprints with Briar.

Unfortunately we didn't go through the box until we had left the hospital, so there was a lot in there that would've been really helpful to have gone through. And so I've since given feedback to the hospital that the staff on the maternity unit would be really beneficial for them to go through the boxes to best understand what they're giving bereaved parents and help them walk through it and make these decisions.
There's a children's book in it that you can read to your baby. We didn't find that out until Briar had already gone off for the autopsy. There was a book that's really beautiful, it's love letters from other loss parents and just helping, really make us feel like we weren't alone. That the depths and the darkness and all the grief and sadness that we're feeling, other people have felt that as well.

There's a book that I do recommend, that's *100 Practical Ideas on Healing Your Broken Heart*. And that was really helpful because we had picked one every day and that helped us mark the passing of time. There were resources in there, notebooks, chewing gum, which would've been nice to have while the hospital and we weren't brushing our teeth.

Our care provider offered us social worker support, but the social worker never knew that we were offered that support. So six weeks later, I eventually called them and was like, why haven't we heard from you? And they said, we didn't know that you wanted to hear from us. That's another way that you're getting let down. So something that needs to be mitigated.

Yeah, we, unfortunately, our hospital and a lot of the hospitals don't have cuddle cots. These are bassinets that keep your baby cool so that you could spend more time with them in the room. Because we didn't have that, because we were requesting an autopsy, we got very limited amount of time with Briar.

We held her maybe for an hour the first night, and then she was taken away to the morgue. We got a hold her the next day for probably another hour, and then she went back to the morgue and, at that point, we'd been able to get most of our parents to the hospital.

And then the last time that we held Briar, our parents got to hold her and meet their granddaughter—on my side of the family she's the first grandchild. So that was, that was

a lot, but I'm really grateful that my parents got to meet her. And then we had to say goodbye, and leave the hospital with no baby. With a box.

Yeah. Yeah. I'm very grateful that we didn't hear any babies or joyous moments while we were in the hospital. We weren't in a separate wing I think it was just a quiet time.

ERIN BOHN: Sorry, you were still in the labour and delivery wing?

ERIN SOWERBY GREENE: Yes. But yeah, we didn't see any other families or hear any other families. But I've heard other stories of people going through the worst moments of their life and hearing people having the best moments of their lives. It's a privilege that we didn't have to experience that.

JAIME: No, no. Thank you for sharing. And what about after you got discharged, you went home from the hospital. What feelings happened for you when you got home?

ERIN SOWERBY GREENE: A lot of numbness. Constant tears. So we left the hospital, I think it was around 5 the next day, just because the silence of the hospital room was just deafening.

So we went home. We started getting calls from the hospital asking for a review of our hospital stay, and I was screening these calls and I just, I didn't want to talk to someone on the phone. I don't know if that's the millennial in me or because I was depressed and vulnerable. I eventually answered, and it was this perky woman who asked how/if I had some time to give feedback on my recent hospital stay, and I told her my recent hospital stay ended in stillbirth and the woman went silent and then said, oh, well better luck with the next one. And hung up.

ERIN BOHN: Oh my.

ERIN SOWERBY GREENE: Yeah, so that was a lot. We've provided feedback to the hospital and to say that the opinions of someone whose hospital stay ends in death, but that they need to be reached out to in a, a way that's less invasive or intrusive. So they're flagging loss files and that they've told me they'll reach out to them in an email or a letter so the loss person can choose if and when they want to respond, but their voice can still be heard.

JAIME: Yeah. Thank you Erin. I experienced many of those things that, that you've shared today, and I, I think the feedback is so important and even more so than that is the actual change. And that's really what we as loss parents need to, to see is the change needs to happen and the feedback needs to be taken to heart.

ERIN SOWERBY GREENE: What has been really incredible is that there has been, so Briar died just about six months ago, and there has been real change made in real time, including the hospital survey, as I mentioned.

We've also got a hold of the hospital foundation and my husband got quotes about different cooling bassinets and we looked at Cuddle Cots, which are from the UK, and Caring Cradles, which are from Florida. Got some quotes, the pros and the cons. We

called different hospitals to find out which systems they had and what they liked and didn't like about it.

And then worked with the hospital foundation to set up a fundraiser in Briar's name, and we were able to raise the funds for one Cuddle Cot in less than a day. It was so nice to see how many people love our little girl and want to support us.

Uh, and yeah, so we're trying to keep that momentum going cuz we hit our goal and surpassed it and we now have identified three other local communities that need a Cuddle Cot and we're gonna start fundraising for them.

JAIME: That's amazing.

ERIN BOHN: Yeah.

JAIME: And look at how Briar is sharing and, and just impacting unfortunately future families.

ERIN BOHN: Absolutely. So one thing that I would love to talk about is lactation after loss. Were you walked through any of that at all? Or how did you care for yourself as a mom?

ERIN SOWERBY GREENE: Yeah, that's something that I think a lot of people forget happens. That even though you don't have a baby to take home, you still have milk, that your body still thinks that you gave birth to a baby. My body was very ready to be a mom. I started producing colostrum at 16 weeks.

One of my care providers, I think it was 24 hours after the birth, or perhaps 48 hours after the birth, they came to our house and did a, a visit. But at some point they did discuss, yeah, that your milk is gonna come in. It was also in one of the pamphlets in the bereavement box. That I did not read, but my milk came in.

I feel like it's more common perhaps in in moms who have had a live child and then a loss who may choose to pump and donate. But for me, I just wanted to start trying to get to my new normal, and I didn't think I could have this constant reminder of what I didn't get to do and what I didn't get to have.

I was told that if it gets unbearable, you could hand express a little bit to help relieve the pressure, but not to fully express because then that's just gonna continue that feedback loop of your body thinking it needs to continue to produce milk. But yeah, I did not dry up quickly. At six months later, there's still a little bit there.

JAIME: Wow. So much to share. When you're talking about lactation, I just, it takes me back. My first loss with my son James, was my second pregnancy, and I was not expecting milk to come in. I'm not sure why I couldn't piece that together myself, but that was, I can remember that being shocking for me and not having been told at the hospital that this will happen and this are, these are some of the things we need to do.

ERIN BOHN: And I've gotta say Erin, I am honoured to talk to you, to talk to someone like yourself who is so fresh in the bereavement and it is amazing how beautifully you share your story. The good, the bad. You are so eloquent with your words. We can feel the love.

ERIN SOWERBY GREENE: Thank you.

[music fade in]

JAIME: We reached out to a registered midwife with experience supporting families living in urban, rural, remote and Indigenous communities to learn more about practices bereaved families should be able to access after a stillbirth.

[music fade in]

ANNE-MARIE : My name is Anne-Marie Cayer and I'm a registered midwife practicing in BC. Some practices that I think bereaved families should ideally be able to access after a stillbirth include things like culturally safe care, support for ceremony, other family-chosen ways of moving through this really tragic time.

I sometimes see families pass some of their power over just by stepping into the institutional setting. There's an idea that you're being cared for by professionals who know best, and I just think that families really need to be held up to lead their care and lead their time at the hospital. Sometimes that means really highlighting for them that they are invited to practice ceremony or invite elements of their culture into the experience.

I also think that all bereaved families need to be given a balance between having privacy and also access to compassionate support at this time. There's such a level of shock that can be present for the families and caretakers alike. All of us, whether we're in the caretaking or care-receiving role, can benefit by being reminded that there often really is time to make decisions, time to ask questions.

I think ideally, families that are grieving a stillbirth should have space apart from other childbearing families, so they shouldn't necessarily have to be surrounded by other living babies or other families that are breastfeeding living babies. That can be really hard and triggering for families to not have space from other folks who are going through the same thing, but with a happier outcome.

Lots of settings will have a perinatal loss symbol that can be put on the family's chart or on the door so that everybody interacting with this family can be sensitive to what's happened. And that includes cleaners and kitchen staff, uh, technicians, just working within the space to make sure that anybody that the family encounters is aware.

I think every family deserves support and access to help in knowing how to care for the baby and make decisions for the baby, handle the baby, things like that. Depending on the circumstances of the stillbirth, many folks will have never seen a stillborn baby. They won't know what to expect the baby maybe to look like. What kind of state their body

might be in, and just frank conversation and support around that is something that all families should be able to have access to.

As well as, I think many places it would be standard to offer bereavement gestures with respect to the baby's body. So often we'll offer clippings of the baby's hair, footprints from the baby, photos to be taken. And sometimes families aren't sure if they want that or not. And sometimes it can be appropriate to go ahead as a care provider and do those things with the consent of the family and keep it, and they might choose to take it home with them or, or they might choose not to, because often what families need changes over time.

2Also, maybe lastly, just making sure that people are sent home with ongoing care. The immediate medical care around the experience of a stillbirth is one thing but the ongoing care for the family and resources being provided for family for the days, weeks, months, sometimes years ahead, is really important.

I would say there is a tension between what bereaved families potentially want and what hospitals can allow for. They might be experiencing shock, really hard-hitting waves of grief. And have really different questions about this impact on their life that has nothing to do with the medical investigations that might be talked about and offered.

There certainly can be resource problems that are really problematic. We know that families experiencing stillbirth, it is potentially one of the most traumatic experiences that they might have in their life. And yet they're often going through that experience surrounded by a care team and in an environment that isn't specialized for such profoundly tragic circumstances.

We can be under-resourced in really supporting grief. So for example, families who go through the delivery of a stillborn baby in urban versus rural locations certainly may have different experiences. For example, in Vancouver, you would have access to care providers that have supported families through this experience more often than potentially at a smaller rural or remote site where just because of the volume of people that they care for, they might not have as much experience. So maybe in some ways families who deliver a stillborn baby in an urban or higher level care centre may have access to more experienced care providers and more resources.

Although I have to also suggest that sometimes in rural and remote sites, there are care teams that really excel in providing personalized care. And sometimes aren't as, uh, busy on the floor with multiple complex situations going on, taking their attention away from the family. And so I think there's of course, the possibility that despite a lack of infrastructure and resources and experience in a smaller site, you might access incredibly individualized care in a rural site as well. For example, social work support an example of different infrastructure.

The number one thing that I think clinicians, midwives, and other caregivers should be thinking about when it comes to supporting families that have experienced loss is to remember that these are still parents. When a baby dies, that baby is still making parents

out of their family. Maybe they're already parents to other children. Maybe this is the rite of passage that made them parents. They are parents. We need to treat them just like we would treat other parents with respect, time and space for decision-making and compassionate care.

I think sometimes as care providers when there's a perinatal loss, we also feel a lot of similar feelings to the parents. Shock, grief, questioning, fear of what unfolded medically. Sometimes a sense of trauma about what has unfolded, questions about whether it might have been preventable. And it can lead care providers to not always be the best support people for the families undergoing loss.

And it's important for care providers to remember that these are parents that we're there to support and we need to access our own support to be able to do that job well. We need care ourselves as care providers when we go through these experiences. They're often not common in our careers and they impact us a lot.

[music fade in]

JAIME: So, Erin, if I can circle back if you could give any message to care providers about dealing with bereaved parents during and after delivery, what would you say?

ERIN SOWERBY GREENE: Just treat us like we are your brother, or your sister or your daughter. Treat us like people.

I understand that a lot of medical training includes creating that separation between profession and emotion. And I was very candid with one of my care providers that it meant the world to us to see your heart breaking alongside us. It may not be professional, but that made us feel seen. So yeah, just look at us as more than just a patient. We're a family. We're, yeah, we're lives that are being shattered.

[music fade in]

ERIN BOHN: So Erin, Jaime and I really wanna thank you for all the work that you've done, and especially during your darkest days of grieving Briar. So, from two mama bears to another mama bear, we think you're incredible. Absolutely incredible. So please take care of yourself.

JAIME: And thank you so much for sharing Briar with us and everyone today.

ERIN SOWERBY GREENE: Thank you so much for having us.

JAIME: And thank *you* so much for joining us to listen to Erin Sowerby Greene and Anne-Marie Cayer. Please join us whenever you can and share this podcast with anyone who needs it. Take good care of yourself and talk to you soon.