Anne Nicholson Weber: <u>00:00</u>	This is episode 16. Thanks for joining me. In this episode, we're talking about the challenges facing parents whose newborn needs to spend time in the neonatal intensive care unit and talking about some coping strategies that can help. I hope you'll stick around. Welcome to the BirthGuide Chicago podcast, conversations about building your circle of support in the childbearing year. We connect you with experts in our community who can help you conceive, stay healthy during pregnancy, have a safe and satisfying birth, and embrace the joys and challenges of becoming a new family. I'm your host, Anne Nicholson Weber and the founder of BirthGuideChicago.com, where every month, thousands of Chicago area families find relationship-centered care, from conception through the postpartum period.
Anne Nicholson Weber: <u>00:58</u>	Today I am talking with three perinatal providers who have special insight into the challenges that families face when their newborn requires a stay in the neonatal intensive care unit, which is the NICU. Jackie Bellefontaine is a licensed clinical social worker who practices with Matrencence therapy. She has been a NICU social worker for three years, working directly with families while in the NICU, and also works with other families post NICU stay to support them on their journey post discharge. Cameron Lacyy is the owner and founder of Intuit Healing, a wellness center in Chicago, focusing on balance for mind, body, and soul. Cameron is the mother of two daughters 17 months apart, who both stayed in the NICU due to lung issues. Her experiences have made her an advocate for postpartum care. And finally, Tara Lattanzi is a licensed clinical social worker who works as a therapist with Crescent Moon Therapy.
Anne Nicholson Weber: 01:51	She supports individuals and families during the perinatal period and beyond. She also has worked as a NICU social worker, is certified in infant mental health and has extensive clinical experience with infant parent dyads. I'm so pleased you three have joined me to talk about this. Thank you. I imagine there are several populations who find themselves in the NICU, and one is families who knew there might be issues and had some chance during pregnancy to prepare for the possibility or likelihood of a NICU stay. And the other is families who something happens during, uh, labor or unexpectedly and they find themselves in the NICU with, with no, uh, preparation. So maybe as a place to start, um, Jackie, you could talk about how you see those two populations as different, whether there's anything that a family not having any high risk factors can do to allow for the possibility of a NICU state or maybe they shouldn't. What's your, what's your thinking about that?

Jackie Bellefontaine:	<u>02:52</u>	Yeah, um, I think it comes up a lot when birth givers are sharing with me. 'It was a normal pregnancy. Everything was fine. And then one day I went in for an appointment and I never went home.' It comes up a lot. And I think what's difficult about that is just like the uncertainty and then also too, just the inability to plan for anything. Especially if, for example, lots of, um, families are admitted from the clinic to the antepartum unit, so before they deliver, and they're there for who knows how long, which is super difficult, right? Like if there's other kids at home, for example, people have shared with me like, I, I don't know what to do. I can't be here because I have other responsibilities. I have other family members. There's a hierarchy of needs and like they, like we can't talk about how much anxiety, for example, when she has to go home because she has another kid.
Jackie Bellefontaine:	<u>03:43</u>	Um, so I think for that it's just a lot. And I think it comes with, uh, an unexpected say maybe like frustration if it's just like not what we planned for, um, is something that gets shared a lot and then just an unknown. And I think a big difference is, um, when, for example, someone knew that they were getting induced at a certain gestational age or when they, it was a pre-planned admission. Like they knew because of some condition, they were already kind of expecting it already, kind of knowing sometimes what people have shared with me that's been helpful is that the NICU team will see them before they deliver and kind of give them as much as they can, an estimate of what the plan of care is going to be, what it might look like, what they know at that moment, what the goals are to go home.
Jackie Bellefontaine:	<u>04:29</u>	Um, and I think a big similarity probably across the board for a planned admission versus one that no one expected is the uncertainty in that going home is really just up to the baby. It's up to the baby, baby will tell us when they're ready. It's up to them. We're on their timeline. And I think for a lot of people it can be frustrating because sure, you can, you know, plan the best that you can. But if something's happening where the medical team doesn't feel comfortable or ready to send baby home, then it's, it kind of throws a wrench in what you were planning.
Anne Nicholson Weber	: <u>05:00</u>	So you're saying that obviously there are additional uncertainties and anxieties for a family that wasn't expecting it because there are all these practical problems they just haven't expected to have to deal with. But for all families there's this uncertainty about how long the baby might be there and what outcomes will be. And that's obviously going to be very

		challenging. Cameron, I know that you yourself had two babies who had NICU stays. Were those expected or unexpected in your case?
Cameron Lacy:	<u>05:28</u>	Um, the answer is both. So I had cholestasis with both of my children and my firstborn. It was, it was understood. She got induced at 37 weeks and we knew she had a high possibility of going. We never had a visit from NICU folks, but um, she, she was too purple after like 45 minutes of being born. And so they swarmed us and took her and she spent about four days there. So, um, it was like, I knew it was a possibility because of my condition, but it suddenly happened. Um, then my second, again, I had cholestasis and it was, I, it was planned. I'm like, okay, been here, done this. Like let's plan for it. Met with the NICU team. I actually ended up in antepartum because she tried to come at 32 weeks and that is where I begged and pleaded <laugh> to leave and go home 'cause I had another baby and we don't have family here.</laugh>
Cameron Lacy:	<u>06:43</u>	And it was like a friend watching my toddler. I was able to go home and was on bed rest. And at 35 weeks my water broke and I had a 90 minute labor and I have a second born child, <laugh> and she was in the NICU. And um, so it's a mix of both. The answer is, like I don't think the NICU, no matter who you talk to like, just to piggyback off of what Jackie's saying no matter how well you plan or who you talk to or how you wrap your brain around it, every experience is shocking because the NICU is not meant for parents whatsoever. It's meant for the babies, it's meant for the children. But you are still watching your child be in the NICU and it doesn't matter how short of a stay, how long of a stay, how well prepared you are. Um, it's horrible.</laugh>
Anne Nicholson Webe	r: <u>07:40</u>	Yeah, very challenging. Tara, anything you want to add to either of those responses?
Tara Lattanzi:	<u>07:46</u>	I think, you know, when you're entering into a period of pregnancy <laugh> and you're a parent, it is so scary. Um, and I think it can be helpful to think about different outcomes and different scenarios. I think it also can kind of add to our anxiety if we're looking up every worst case scenario of course. And so I work with families a lot during that period of not knowing, um, around what does it look like for you to feel calm in your current position with what we know about what's to come. And gather some support around you so that if things do get hard, you know, if at all possible, if we have the resources for it, there are people we can reach out to. We have backup plans for children at home. So I think what I think about a lot is filtering how much</laugh>

		information we take in, but then also making sure there's a safety net of support around us during times when things feel a little bit calmer, um, if at all possible.
Anne Nicholson Weber	:: <u>08:56</u>	So it seems like we've touched on two whole realms of challenges and one is the practical, um, and the other is the emotional. Do any of the three of you have helpful suggestions about the practical issues? Like what are some of the things that families can do that might not be obvious as ways to cope with the demands, the practical demands of the situation?
Cameron Lacy:	<u>09:24</u>	Um, for me, find a babysitter if you have another child, particularly a friend or someone in your community, whether it's a family member or whoever, that your other child is extremely comfortable with and they're cleared with daycare. And have practice stays just in case something does happen, that you have to be there. Um, and I think the other practical thing is utilize the NICU for all that it is. With my first one, we ran ourselves ragged. It was like the worst five days of our life. We were 'cause when you, when we left the hospital, we got discharged. 'cause insurance doesn't want you to stay longer, even if your kid is there. Um, like that's the farthest away I ever was from my child, ever. And it was extremely difficult. So we were always coming back around the clock.
Cameron Lacy:	<u>10:27</u>	'cause you can be there as long and often as you want. But when my second one came, I went home and slept and I pumped and I didn't allow myself to feel guilty for that. Like I still had, you know, the postpartum hormone come down and the pain of that. But I allowed myself like, this is the gift of rest before my child comes home. Because every single person that's in that NICU, nurse, intern, doctor, whoever, their entire job is to help my child be successful so that she can come home with me. And that was just like the mantra I kept telling myself so I could be better prepared when she came home.
Anne Nicholson Weber	:: <u>11:12</u>	So essentially pacing yourself and recognizing that you can't be here all the time and need to take care of yourself as well.
Cameron Lacy:	<u>11:18</u>	It's okay to let other people take care of your kid. And I know that is like, that's like the hardest lesson to learn, especially for new parents because you made this entire thing and now they're outside of you and nine outta 10 hooked up to cords and being prodded and all of these things. It's, it's a very difficult practice, but you have to practice. Yeah.
Anne Nicholson Weber	:: <u>11:43</u>	Jackie, do you want to add anything to that?

Jackie Bellefontaine:	<u>11:46</u>	Yeah, Cameron, it's nice to hear a parent's perspective on that because obviously we preach it in the NICU all the time of like, you know, it's really important that you go home and take care of yourself. And parents who are there for a while are like, I just can't. And I've found myself kind of noticing, like, I can't really argue with you. Like I, I can't imagine that I would, I probably wouldn't do anything different. Um, but it is nice I think to hear, maybe in retrospect, that some form of really trying to hold space for like, yes, this is very hard and you know, it is up to you. Nobody wants you to leave. You are mom, this is your baby. It's not, you know, taking away any of the love or the care, the support that you can provide your baby.
Jackie Bellefontaine:	<u>12:33</u>	But at the same time, just like you said, parents feel like if I'm not here, I don't deserve to rest. Or, well my baby's in the NICU so why should I deserve to rest or have a meal and shower. And I just kind of, it may be super cliche, but I always just like, you have to be your best self to care for your baby's best self. But I mean, it's nice to hear that, I think. 'cause I, I don't know if a parent would be like, you're being very annoying in saying that to me. But I guess it's kind of nice to hear that some parents are like, yeah, I get it, I've learned that it's okay.
Anne Nicholson Weber:	<u>13:07</u>	You can hear things from peers that you can't hear from professionals. Yeah. Cameron,
Cameron Lacy:	<u>13:11</u>	Can I say something to that? Like, for me, Jackie, it was like I had, I had two back to back and the second one what put me at ease was, our head nurse made sure that we had her cell phone number. She was texting me, she was like, baby just woke up, she's good. Here's a picture. And so it felt like I was there even when I wasn't there. So like I could shower, you know. Because the first time I was in the NICU, I mean I think what people don't really realize, like you can be like, oh, you're in the NICU, they're taking care of your baby. They're going to get well and you're going to leave hopefully, right? No, I just had a child and I had to walk myself because they wouldn't let anyone wheel me. And I had to walk the entire length of the hospital to get to my daughter to then sit and learn how to breastfeed with no one's help.
Cameron Lacy:	<u>14:06</u>	I have no idea what's happening. I don't know what's happening to my body or anything. It all felt so invasive and like I was discarded while simultaneously being like, you're the mom. Are you providing milk? Are you pumping? What are you doing? Are you resting? And it just felt like the expectations are coming from every single angle and they're so high. And meanwhile, all you can think as the birthing person is, I'm as far away from my

		child as I've ever been and I don't know what I'm doing at all and no one is helping me. So it's like, I hear what you're saying, but like that extra care, like I can see in like the clinical staff how difficult that is. Like it's not just my baby. They're taking care of, they're taking care of hundreds of babies and hundreds of moms and fathers and like a range of severity, right? But like, man, those text messages were a lifesaver, you know? Mm-Hmm
Anne Nicholson Webe	er: <u>15:07</u>	Mm-Hmm <affirmative>. Well even that just seems like such a helpful, um, I guess I could almost call it a tip that that's something you might be able to ask for. That communication from the unit can be so reassuring, and allow you to, to get away. This all sounds so hard. Obviously I don't have this experience personally, and it, um, you're painting such a vivid picture, Cameron, of how challenging it can be. Tara, did you want to add anything to what we've said so far?</affirmative>
Tara Lattanzi:	<u>15:38</u>	I think just to echo that, you know, telling someone to go home and rest when their instincts are screaming, stay <laugh>. You know, we also have to trust our parents and what they say they need in any given moment. Um, and maybe they do need a little bit of encouragement to step away, but I also think it can be a hard space to have validation that your instincts are yours. Especially as the birthing parent, because someone else is taking care of your baby <laugh>. You know, and you're, you can be there, but I think as much as possible, it's important to give space for your own instincts. Um, and sometimes it can be hard to parse out what's my instincts and what's my, like fears, right? <laugh> and guilt. Um, but I trust that birthing parents know what they need when they need it and sometimes need a bit of encouragement.</laugh></laugh></laugh>
Tara Lattanzi:	<u>16:39</u>	Um, but I think it's also important to empower parents to do what they need and trust that your situation, I think there can be a little bit of without, you know, realizing a little bit of comparison or expectation even we have for our own selves. It might not be the person next to us. It might just be the standard we have in our mind about what it looks like to be the best NICU parent. Um, and what I would have to say that to that is, that's going to look different for each person. The best NICU parent is the best that you want to be in the ways that you can be. And that's going to look different than someone else.
Anne Nicholson Webe	er: <u>17:15</u>	And that of course is applicable to, to all new parents, to all new mothers. That's not specific to the NICU. Part of the process of becoming a mother is looking around and saying, that's me. That's not me. That, that feels right. That doesn't feel right.

		'cause the range of models and advice out there is so staggering. <laugh>. So I really liked, Tara, what you're saying about, um, instincts like, you know, listening to what your inner voices are saying in what is obviously I mean new, new parenthood is challenging for everybody. This is, you know, 20 times more challenging the advanced <laugh> advanced level of making that transition to becoming a new parent. Um, well, what are some of the difficult emotions that parents have to, um, deal with? Uh, and I know you've mentioned guilt and you've mentioned anxiety. Um, are there others that 'cause we're kind of now moving into the emotional side of this. What, what are some of the most challenging emotions and what are ways that parents can address those as they go through this, uh, experience? Jackie?</laugh></laugh>
Jackie Bellefontaine:	<u>18:29</u>	Something I've noticed is, I guess frustration might be a name for it, but I think when parents are I've seen it happen a lot where baby has to stay, maybe something new came up. Um, and I see them kind of going through this struggle of frustration. Like that is very hard for them as a parent, right? Like seeing their baby go through this and having something new come up or a change in the treatment plan that would result in more time in the NICU. Because at the end of the day, they want their baby home with them, right? Um, but it's also conflicted with and I always say this they always want the best for their child. I've never met a parent who's like, yeah, I know they need more oxygen, but I just, I really don't want to come here anymore. No. Even if the parent is expressing it initially as maybe like frustrated or even like angry, like "I don't want, what do you mean?!"
Jackie Bellefontaine:	<u>19:28</u>	"Like, that's not what this other doctor said." It's like the plan changes and they're like, for lack of a better term, they're pissed. And sometimes they'll reach out to me about it and I'm like, of course they're pissed. But I don't think I've ever come across a parent who's like, I don't care what's best for my baby, I just want them home. No one ever does that. It might come out as like, "this is ridiculous. I don't want to do this." It might be like anger, right? That frustration might just be sadness, but the confliction of like, I have to trust these people to help my baby heal and come home. But also like, I'm angry just at the circumstance or I'm sad. Um, so I think a lot of like those conflicting emotions where who wouldn't be excited, right? You're like counting down the days, especially if it's a long stay and if there's a wrench thrown in those plans, it's hard to really just find a balance between those feelings.

Anne Nicholson Weber: <u>20:18</u>		Yeah. That receding horizon is always so difficult. Um, uh, Tara, anything you want to add to that?
Tara Lattanzi:	20:26	Um, I would say fear of course is a challenge. Um, and I, of course I'm a therapist and so I think about like, do we have someone to work through some of these feelings that come up? Um, and sometimes it can be helpful to establish rapport with someone during pregnancy or before so that the emotions that come out, whether your baby is in the NICU or not, um, are sometimes related to our own experiences, um, and our own past and our own childhood and some of these fears that maybe we thought we've worked through. Um, but who wouldn't be on constant alert and constant stress, um, if their baby was in the hospital, you know? So it's, I think it's, it's And how do you cope with that? I think it's, it's tough. And then sometimes, like you described Jackie, I think when things change it can add to the fear and the stress and then it can feel like frustration and anger, which is more of an umbrella emotion that comes out. Um, but I would say, you know, there's a lot of of course who wouldn't be afraid to have their baby in the NICU? I mean, and maybe disappointment too and expectations that are, are feeling lost. Some people feel a very big sense of loss, um, because it's not what they expected. They have this beautiful setup waiting <laugh> at home and then they haven't brought the baby home to be home in that. So I think loss can be the other one.</laugh>
Anne Nicholson Weber	: <u>22:01</u>	Yeah. Yeah. Um, I'm thinking about, um, Cameron, I was going to ask you to talk about I know you do, in addition to psychotherapy, your practice involves body work of different kinds. And then it struck me that it's kind of irrelevant during the time the baby's in the NICU. 'cause nobody's going to, I wouldn't think, have time to go get a massage to try to deal with their anxiety about the fact that their baby's in the NICU. Maybe, maybe that's wrong. I don't know. What would you say to that?
Cameron Lacy:	<u>22:31</u>	Absolutely not. No way. I mean, like to piggyback off of what, like Jackie and Tara are saying, the hyper vigilance is so intense and back to like what Tara was saying about your instincts, like you're constantly fighting yourself because you have these different medical teams coming in and sometimes telling you conflicting information. So one team might be saying, your baby's going to go home in three days, everything's great. And then the afternoon team's going to come in and be like, things have changed. And so you're, you're on a consistent and constant rollercoaster and there's no room for stability for yourself, but your one job is to remain stable and present. And

		that is an impossible task. And yeah, like for me, I, I remember my moment of fear. I remember my moment of anger and I am eternally apologetic to the intern I took it out on.
Cameron Lacy:	<u>23:28</u>	Um, but you know, like I'm a new mother and they're saying an hour ago she's getting ready to come home and I come up with my car seat that she tells me to get, and now she's in for five more days. Like, I, I will never forgive you. Like, don't tell me that she's coming home when you haven't cleared it with someone, that's cruel. And then having to leave the hospital without your child. Like both times that happened. I have never experienced the amount of like sorrow and horror, like it's actual horror to like have grown something for as long as you have, to have gone through the goodness and the, you know, honestly misery of what pregnancy can be, to then just walk away from it, even if it's for just a few hours. 'cause you have to get out of the hospital room. It's insane what you can hold.
Cameron Lacy:	<u>24:26</u>	And as far as like, you know, the question of getting body work, I don't want anyone, I don't even want my husband to touch me. I don't want anyone around me. All I want is my child. And we constantly tell our patients that like, you know, are doing perinatal care, like with body work, that like, I don't want to see you a month after you've had your baby because this is now the time for you to readjust and to reacclimate. To like who knows what their birth story is and also their body needs to come back to a point of like homeostasis. And then when you do come back, I only want to see you for an hour because after an hour they're not there. They're thinking about their boobs leaking, they're thinking about their baby and getting guilty, you know?
Anne Nicholson Weber	r: <u>25:20</u>	Yeah, yeah. In some ways I feel like the title of this was going to be and still maybe will be coping with a NICU stay. It seems like almost what I'm hearing is it's horribly challenging and coping just means getting through it. And then maybe the time for healing and addressing some of what happened has to be afterwards. I don't know if Jackie or Tara, you would want to amend that.
Tara Lattanzi:	<u>25:46</u>	I would just say that if you I have worked with parents who have felt a sense of relief that they could have some time at home to rest. It's not often, but I have worked with families who feel kind of relieved to have their baby in the NICU and then feel bad about it, <laugh>. And so my work with them is, if you feel relieved and you're going to go home and get some rest, like that's exactly where you need to be. Right? So I, I do think that especially if it was kind of anticipated and people are confident</laugh>

	with the care their baby's receiving, some parents do find it as a sense of support so that when the baby does get to them, they've been able to get about 48 hours of rest or whatever it means for them. So it's almost been a source of support in some cases. Um, so I would say whatever the experience is is valid.
Anne Nicholson Weber: <u>26:42</u>	Mm-Hmm. <affirmative> it can be a reprieve. Well let's try to turn to, um, helpful advice essentially. Um, and maybe directing it to a family who find themselves unexpectedly in the NICU. Um, Jackie, you know, are there things that you have found helpful to suggest or share, um, approaches that can, can be useful to a family in that situation?</affirmative>
Jackie Bellefontaine: 27:08	Yeah. Um, I think kind of speaking from my experience being directly in the NICU and then also seeing folks afterward, a big one is, um, I say this all the time, it's my favorite phrase that two things can be true at once. Like you can be very, very upset and at the same time you can also be thankful, right? For like, maybe, well at least my baby's like here and alive. And I think I hear a lot of people kind of talk about trying to have one cover the other. I think a lot of people feel how they should, right? Like kind of talking about like those instincts, like they're, they're kicking in. That's how you feel, you're upset, you're worried, you're almost like, I, I'm sad for myself. And then I think a lot of parents kind of catch themselves and they're like, well at least the baby's here though.
Jackie Bellefontaine: 27:57	Like, I can't really be upset. And I think the thing is like, wherever you are, that's okay. It's okay. Like I know when in a NICU we always talk about, well we're on baby's timeline, but we're also on, you know, the parents' timeline. It's okay to kind of just acknowledge how you feel and it's okay to be like, wow, this really sucks. And you don't always have to be trying your best to just look on the positive. Sure. I would not advise maybe wallow and just like not try and, I don't know, reframe maybe kind of think alternatives. But I think a lot of people try and just mask their emotions with like, well it'll be fine. I don't have to think about this. I'll be okay when the baby comes home. And then when that time does come, those feelings are still maybe present. And I think a lot of people struggle with like, well this was supposed to fix everything and it, now it's not fixed. I mean it's a lot. I think honestly, whatever people feel like they're capable of doing in the moment is okay and just getting through it. But also it's, it's okay to feel how you feel.
Anne Nicholson Weber: <u>29:02</u>	Yeah. Tara, what else might you offer to the families in this very challenging situation? I

Tara Lattanzi:	29:09	I appreciated what Cameron had to say about um, you know, having a team of providers. I think for some parents it can feel hard to ask questions and speak up and, if they have a concern, bring it to the team. So I would also say, um, it's important that you feel that you can advocate on behalf of your baby. And if you don't feel you can, to have someone who you trust come in and help you, like a sister who might be a little bit more vocal or an aunt, because some people don't realize they can actually invite family members in for meetings with their providers. And if you're not feeling confident enough to ask questions in the moment because you're exhausted and stressed, it's okay to also bring people in who could ask the questions that maybe you want to ask, but just don't feel up to in the moment. So I would say, um, especially if you're a person who worries about kind of being the squeaky wheel, it can be challenging to be a little bit vocal, um, and to ask questions. But it's important that you feel like you can do that. And if you can't, I would encourage people to ask for help with that.
Anne Nicholson Weber	: <u>30:25</u>	That's a kind of a variation on Jackie's point of not, um, pushing things down, like concerns voicing those concerns as well as your emotions is part of getting through this. Um, I was so struck, and I think it was, Cameron, you who said the NICU is for the babies, not the parents. Um, that really made an impression on me and I wonder are there ways to, perhaps it's part of what Tara's talking about in terms of advocacy for yourself. Are there things you can do to make the stay better for you as a mother, as a parent? Jackie, maybe you've got thoughts on that.
Jackie Bellefontaine:	<u>31:07</u>	Um, the only thing I'll share is that, um, the way I frame it to parents, when I meet them for the first time, I always check in just to get a sense of how they're feeling with their relationship with the medical team. And I kind of frame it like, yes, the baby is their patient, but they, they tell you the plan of care. Like they, they answer your questions. They can't ask your one week old baby if they could send to a PICC line, you, they can, you consent to the PICC line. And so I just kind of am like, just keep it in mind that like you can ask them questions like you, it's okay. Like, they answer to you. My goal in that is just also kind of to highlight that you're in this just as much as your baby. I mean, my goal is to kind of build confidence in that's your role and just kind of remind them of that and kind of hopefully give them some kind of agency back if they feel like, um, they might lose it in the process.
Anne Nicholson Weber	: <u>32:06</u>	Yeah. Cameron, do you want to say anything more about this?

Cameron Lacy:	32:12	I mean, I have a lot to say <laugh> about this. Like, I think, um, having a child or being pregnant is innately political and I think it's a massive failure of our healthcare system. The lack of support that is given to birthing folks, especially in the NICU. Like, um, Jackie, I know you said like one of your roles is you're a mental health provider inside of the NICU, and I never met one mental health provider. I never met one, um, lactation consultant, anything. I had to hire a postpartum doula in order to get the care that I had. And even that turned into more of a therapy role. Um, you know, back to the emotional part, like allowing yourself the space to mourn and somebody giving you permission to do that instead of being hypervigilant, I think would've changed my postpartum experience. 'cause I immediately inside of the NICU became postpartum anxiety, which was a very quick slide to postpartum depression, which, you know, becoming a mother changed my life.</laugh>
Cameron Lacy:	33:22	But postpartum depression changed my entire spirit, you know, um, for the better. But it was a very difficult path and I attribute a lot of that to genetics. But the NICU, um, I believe, I believe that I, I wish that the NICU was also for parents. Um, I believe that there is a world that, um, there can be access to support. I was told, you know, we have this text group, but the text group is down. We have this, but they're out of office. You know, I, I advocated, I looked for resources and just being in the industry I am, I was able to find that for myself. But it's very difficult. And you know, the reason I say the NICU is for the kids is because that's what I was told. I was told that by doctors. I was told that by nurses. I was told that as a coping mechanism for myself so that I could have the compartmentalization of my mother instincts to be like, oh, it makes sense why I am waddling the entire length of this hospital with zero care or help.
Cameron Lacy:	<u>34:46</u>	It makes sense that I am falling asleep in a chair and not allowed to eat here even though I'm learning how to breastfeed. It makes sense that they told me my child was coming home with me and an hour later they're not right because it's for them and it's not for me. And it is a very hard mental space to live in. And there are staff that you will find that care about you as a mother or as a father. In my experience with over 30 days in the NICU and two children, I found two, um, at one of the best hospitals in the US. So, um, my advice would be to resource yourself and always, always, always get a doula because doulas are there for your partner and doulas are there for you. And doulas help fill in the gaps that our medical system do not for women.
Anne Nicholson Weber	: <u>35:51</u>	It's striking because I think, Tara, in your um, introduction that you gave me, the text to introduce you, you talked about the

	mother-baby dyad and your experience with that. And I think what you're describing, Cameron, is that in the NICU the dyad gets lost because the baby is in extremis. And that does seem like a, a really terrible shame to me. Um, and your advice, what I'm hearing from the three of you is, okay, this is not ideal <laugh>, um, but here are the things that you can try to do to fill the gaps for yourself. And one is to, um, I guess is it typical, does every NICU have a social worker or is that, uh, not the case?</laugh>
Jackie Bellefontaine: <u>36:34</u>	I thought it was the case, but as I've spoken to more and more people, um, I don't think it's always the case. But I'm sorry that was your experience, Cameron. I mean I, yeah, I think that in, I mean the one NICU I've been exposed to, there is an attempt to try and make it as family-centered as possible. And to hear that that wasn't even like a consideration is, is disappointing. I'm sorry that that was your experience.
Anne Nicholson Weber: <u>37:03</u>	I know that um, some NICUs have, um, beds for the parents. That's kind of a newer thing, but I think there are some hospitals in Chicago where that's the case. If, I suppose if you're high risk, that could be a thing to think about. Like if you think there's a decent chance you're going to end up in the NICU, then understanding that the care may not be the same in every NICU and that the level of concentration on the mother baby dyad vsr just the baby could be a cultural difference. Um, and then so I was going to say reach out. Uh, one of the things I'm taking away is that you may find a social worker in the NICU and that could be someplace to start in terms of finding support for you as the parent. And then Cameron's point that you can build your own team. Obviously that requires resources and at a time when you have no resources emotionally or in terms of energy. But um, it seems much better than trying to go it alone. Um, Tara, is there anything else? Oh Cameron, you want to say something?
Cameron Lacy: <u>38:04</u>	Yeah, I just want to say like one thing 'cause I think we're all here around the mental health profession with uh, perinatal care and we're talking about the NICU. I just want to stress the importance of mental health care for the birthing person after a NICU stay. Like during a NICU stay, I personally, from my own experience it was the same thing as body autonomy. Like I didn't have space to discuss, I didn't have space to process. But um, being able to talk to a person that understands and can help hold space with these experiences. Cause like what you're talking about, like the dyad with the mother and daughter, I have fought for three and a half years to rationalize my relationship with my daughters. And I have great relationships

		with them, but it's very difficult 'cause I did not, I did not have the experience, um, not that I necessarily wanted, but it's like my children were covered in cords, you know, like it it was a very di I had to leave, I had to leave my babies.
Cameron Lacy:	<u>39:14</u>	That's a very different, um, parenting experience and to have mental health professionals support you in the development of that relationship. I think it is foundational for the rest of your parenting experience. Because girl, it's just going to get different <laugh> as the years go on, you know. That's all I wanted to bring up, it's super important. It might not seem like it because you have this baby to tend to and everything, but like you really need to make an hour once a week for you and you need to have a partner that prioritizes that, because it's one hour that can change your life and all of your relationships.</laugh>
Anne Nicholson Weber	r: <u>39:56</u>	I'm so glad you, you, uh, said that. Cameron, Jackie and Tara, is there anything we haven't covered that you think is important, um, to add before we close?
Tara Lattanzi:	<u>40:06</u>	Yeah, just to add on to what Cameron is saying, I think there can be the challenge with bringing a baby home from the NICU and managing some of those really fussy periods of time and kind of learning how to soothe and help regulate your baby. And the feelings that come up when we hear a baby cry are just really real. Um, and sometimes they're much more related to our own feelings than maybe how uncomfortable it could be for the baby in that moment. So I agree with Cameron that it can be helpful to have some support around that. Things that are coming up for you when you have your baby home and you are doing the day to day. And it can be the time where we choose to forego therapy because we feel like our babies need us more and we can't give up that time. Um, so it can be a very challenging decision to make. But I, I think a lot of therapists are doing virtual and I often have babies on my calls <laugh>, so, and it's nothing that I'm, you know, I think most therapists would understand and appreciate that you need to hold your baby during a therapy session sometimes. So there are ways to kind of do both and <laugh>, um, so I agree with Cameron that it will support your relationship if you're feeling supported.</laugh></laugh>
Anne Nicholson Weber	r: <u>41:34</u>	Well this has been really kind of eye-opening for me, I think, because um, if you haven't been through it, I don't know that you bother to imagine what it must be like. And I think the takeaway I'm hearing is to accept that this is, um, hugely difficult, really feels wrong and <laugh> awful. And both to allow those feelings and to um, kind of pragmatically find ways to work through them with support, to find support you need</laugh>

practically and maybe even more importantly emotionally. This has been really interesting and helpful. Thank you so much for joining me. Yeah, thank you.