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TRANSCRIPT

# Bridging the NICU to Home: A Team-Based Approach to Infant Discharge and Follow-Up Care

## Part 1: Implementing a NICU Discharge Planning Program: Evidence-Based Guidelines

*Editor's Note: This is a transcript of an online course released in September 2026. It has been edited for clarity.*

### Implementing a NICU Discharge Planning Program: Evidence-Based Guideline

**Dr. Smith**: These guidelines are the focus of the talk. The National Perinatal Association developed evidence-informed guidelines between 2017 and 2021. In 2017, they convened a multidisciplinary work group, conducted an environmental scan and a literature review. This year-long process included monthly calls to draft the guidelines, identify gaps and build consensus around discharge preparation standards. In June of 2019, the first national summit, consisting of 16 experts from 14 organizations, reviewed the discharge guidelines across 4 topic areas: home and family assessment, special circumstances, social support and transfer of care. In that summit, they provided feedback on the content appropriateness, completeness, practicality and clarity. In 2020, a small group verified all of the references and assessed the level of evidence for each of the recommendations. In January of 2021, a second national summit, consisting of 22 experts from 19 organizations, reviewed the revised guidelines across 5 topic areas and refined the recommendations.

The outcome is evidence-based, multidisciplinary, consensus-driven guidelines published in the *Journal of Perinatology*. The goal is to standardize discharge preparation and to reduce family stress, improve satisfaction and enhance patient outcomes, making going home a joyous celebration and not a time of uncertainty.

The recommendations were derived from a mix of published evidence and structured expert consensus. This is because there is a limited amount of high-quality evidence supporting the various aspects of NICU discharge preparation. The guidance covers technical infant care skills, family and home readiness, community coordination, transition of care, and follow-up care. A rigid discharge process won't work for every family in the NICU, so the guidelines emphasize that execution depends on the individual family's needs, the NICU's team's make-up and skills, and what locally available programs and resources are available.

There are 5 interdisciplinary sections that guide each family's transition from the NICU to home: basic information, anticipatory guidance, family and home needs assessment, transfer and coordination of care, and special circumstances. The guiding principle across these domains is the recommendations are intended to be adaptable and actionable. No single program works for every family. These guidelines are designed to be both adaptable and actionable, tailored to each NICU's teams, resources and the unique needs of each family.

This chart shows hospitalization rates within the 30 days, 90 days and first year of life, categorized by gestational age, divided into early preterm, late preterm and term. The authors linked birth certificates for more than 6.6 million California infants between 1993 and 2005 to discharge records across the first year of life. Within the first year, 16% of early preterm, 12.5% of late preterm, and 9.5% of term infants had at least 1 hospitalization. It's important to note that even late preterm infants, who are often discharged on a term-like timeline, with a median birth stay of about 2 days, are still physiologically vulnerable, and also have a higher readmission rate than term infants. Ultimately, the risk for all preterm infants for readmission is about 3 to 4 times higher than for term infants. Most preterm infants are readmitted for respiratory complications, while late preterm infants are often readmitted for feeding difficulties. This is why there's a need for strategies that optimize discharge planning and reduce the postdischarge complications.

What is discharge planning? NICU discharge readiness is the attainment of technical skills and knowledge, emotional comfort, and confidence with infant care by primary caregivers at the time of NICU discharge. NICU discharge preparation is a process of facilitating discharge readiness to successfully make the transition from the NICU to home. NICU discharge readiness is the goal. NICU discharge preparation is the process. A key principle in the discharge planning process is that discharge planning begins on admission. Throughout the discharge, each family participates in a comprehensive program tailored to their and their infant's specific needs. Successful discharge

planning programs require multidisciplinary team involvement, anticipatory guidance provision, predischarge needs' family and home assessments, as well as transferring coordination of care for both the infant and the family.

This first section or pillar of the guidelines is basic information. This is the content of education that families receive, the tools and people that are involved in delivering education, and the process in place to ensure success. Discharge education includes both technical skills, such as feeding, and knowledge, such as recognizing illness and who to call when the child is sick. NICUs should have tools and resources for discharge planning. These structured templates can be individualized to families and should be written in plain language and in the family's preferred language. Because personnel differ by unit, the recommendation is to focus on functions and roles, rather than titles like discharge coordinator, planner or case manager. Designated staff should own tasks like DME ordering, appointment scheduling, and family education. Ensuring family involvement is key. Teaching should be scheduled around caregiver availability, with advance notice and flexible scheduling.

The next section is focused on anticipatory guidance, which is intended to help families to build a realistic picture of daily life after discharge. For example, NICUs provide families with a first-week-at-a-glance calendar with feeding times, medication times, appointments, plus a clear breakdown of which visits happen at home vs in the office. Set expectations about infant behavior, reminding caregivers that both the baby and family need time to adapt. Things are dynamic, so feeding and sleeping patterns may shift after they move home. Additionally, families should receive education on expected developmental milestones, potential challenges and recommendations to support development and typical vs atypical preterm infant behavior. Soothing strategies are important teaching points, as coping with a crying baby while being sleep-deprived is challenging.

Support families and caregivers in recognizing mental health issues and addressing financial burden associated with NICU stays and ongoing care. Emergency planning should be concrete: who to call, for what and when. The guidance suggests a color-coded acuity aid, green for wait until the next scheduled visit, yellow for call the pediatrician now, red call 911. Normalize discussions of parental mental health. Posttraumatic stress is not solely a military combat disorder, but a normative reaction to extraordinary circumstances, such as a NICU stay. Finally, financial guidance should be provided to every family, regardless of their perceived means. Final bills arrive well after the baby is home and most families are unprepared to navigate them.

The next section is the family and home needs assessment, which is a structured process for evaluating the medical, physical, psychosocial and mental health needs of both the infant and the family, as well as connecting them with community resources. All families should be screened for social determinants of health and risk factors, at a minimum, on admission and as part of the discharge planning process. Most often led by a social worker or other appropriate staff, such as a psychologist or discharge coordinator, a multidisciplinary process is recommended. The person conducting the assessment needs to be aware of their own explicit and implicit biases and must respect the family's lived experiences and right to disclose or not to disclose.

When talking to the family, explain the needs assessment and then ask for permission to proceed. For example, the staff member might begin with an invitation to talk about the family, and who is helping them, so that the next steps can be planned for together, followed by open-ended questions about housing, who lives in and visits the home, nearby support people and how care is paid for. Throughout the process, maintain family confidentiality and limit sharing assessment results only to those who need to know.

Some general components of the family and home needs assessment are things like the family living arrangement, home supplies, things like food, diapers, safe sleep, transportation challenges, needs, childcare needs, nutrition assistance, and then coping styles, caregiver mental health.

Our next section is the transfer and coordination of care. At the beginning of discharge planning, a PCP must be identified and, if the family has not identified one, the NICU team should work with the family to help them find a PCP. Within 48 hours of discharge, the NICU staff should contact the medical home with a discharge summary, if possible, or, at minimum, with the following information: the infant's name in the hospital and as it's going to appear after discharge if it's different, the infant's diagnoses, any discharge medications and administration instructions, infant feeding and formula mixing instructions, the results of any major procedures, any pending tests, appointments that have been arranged, and appointments that still need

to be arranged, interpreter or communication needs, and any diagnosis-specific to the family, or any family-specific resources or connections. If not provided at time of discharge, the discharge summary should reach the PCP prior to the family's first visit to allow the PCP to familiarize themselves with the document prior to seeing the family. For medically or socially complex situations, involve or update the PCP before discharge and collaborate with them on the follow-up plan. In cases where a social worker is involved, social-worker-to-social-worker handoff is preferred. In situations where there's a medically or socially complex situation, a warm handoff is preferred to make sure the PCP is able to provide the best care for the infant and the family after discharge.

Within 72 hours of discharge, a NICU representative should follow up with the family to assess and support. The call should come from someone with medical expertise, such as a nurse, a trained patient navigator, discharge coordinator, midlevel provider or social worker, and should confirm understanding of the discharge instructions, feeding and how to mix the feeds, medications and their administration, follow-up appointment dates, and reasons for the appointment. Beyond comprehension, the call is an opportunity to ask the family about their general well-being and about the infant's well-being, any anticipated or unanticipated challenges, and referrals or appointments that are needed but have never been made.

The final section is on individualizing plans for special considerations. The guidelines highlight some key populations that may be at risk for falling through the cracks. For families with limited English proficiency, use of certified medical interpreters for all discharge education and discharge planning meetings, preferably in person, then in video, then phone. Family members, never minors, should interpret only when no certified interpreter is available, or in an emergency situation, with a certified interpreter brought in afterwards to verify understanding. For miliary families, records do not move between civilian and military systems unless the families carry them, so provide a copy of the record or clear instructions on how to obtain one for the family. For LGBTQIA+ families, the use of gender-inclusive terms such as parent or caregiver on all forms and teaching materials, and then ask the family members how they wish to be addressed, and confirm in advance that the consent and authorization forms are in place for the nongestational parent, adoptive, noncustodial and guardian caregivers under your state's law. For parents with disabilities, ask about accessibility needs rather than assuming. Parents are usually the experts on their own conditions.

Here are some tips for developing protocols and procedures to implement the guidelines' recommendations in your own NICU. The guidelines call for uniform messaging across staff and materials, written in plain language and free of medical jargon, and reviewed against medical education standards. Inconsistent messaging is a documented source of family confusion and frustration. Separate the universal basic information every family needs, from ad hoc materials triggered by specific infant or family needs. When building a team, identify who owns each role, given your available personnel, and train all the staff on the process, not just the discharge coordinator.

Discharge planning is a process, not an event. It begins at admission and continues until the family is safely connected to their community. The family is the center of the team. Every guideline should be tailored to the family's language, culture, structure, circumstances and belief systems. Preparation goes beyond infant care skills. Families also need guidance on mental health, finance, emergencies, and community resources. A warm handoff matters. Active coordination with medical home and postdischarge follow-up care significantly support a transition success. These guidelines are adaptive by design. Implementation will look different in each NICU. What matters is that the content and the intent reach every family.

Welcome to Bridging the NICU to Home: A Team-Based Approach to Infant Discharge and Follow-Up Care. Thank you for being here today. I'm Vincent C. Smith, a neonatologist and the chair of the National Perinatal Association Discharge Planning Work Group. I'm going to be introducing the guidelines today and will be joined by many of my colleagues who worked to support NICU discharge planning. You'll meet colleagues in the case discussion following that include our discharge coordinator, feeding specialist, family support person and primary care pediatrician. This is the first activity in the 3-part series focused on NICU discharge of the preterm infant. The goal of this portion of the activity is to provide learners with a working knowledge of the 5-section discharge framework recommended in the most recent guidelines. The second half of the activity will focus on a case-based discussion intended to give learners a sense of how these guidelines can be applied in practice. While this program is focused on preparing for discharge from the NICU, future programs will focus on caring for preterm infants in the pediatrician's office, as well as parent advocacy and support. The title of

this session is Implementing a NICU Discharge Planning Program: Evidence-Based Guidelines.

## Case 1: Late Preterm Infant Discharge Planning

**Dr. Smith**: Hi! I'm Vincent Smith. I'm a neonatalogist, and I'm joined by a fantastic team today, Dr. Jill Kasper, a primary care pediatrician and medical home provider, Cuyler Romeo, an occupational therapy and pediatric feeding specialist, Heidi Gates, a NICU nurse and discharge coordinator, and Molly Fraust-Wiley, a NICU parent and a family support person.

The case we have starting off today is a kind of bread-and-butter pediatric case, a neonatology case. This baby was born at 34 weeks, a birth weight of 2 kg which is about the 10th to 50th percentile, is currently 10 days old, so corrected at 35 and 3. And the current weight is 2055 g. During the admission for prematurity, there was some feeding immaturity, a little bit of respiratory distress which was treated with CPAP, a little bit of mild jaundice treated with phototherapy. Currently, the baby is taking full enteral feeds at 150 mL/kg/day of fortified expressed breast milk, taken between 75% and 80% by mouth and the remainder by NG tube. Occasionally fatiguing during breast feeding and occasionally having some feeding discoordination. The growth is regained birth weight by day of life number 7 and is now gaining about 18 g per day. And so this is kind of a bread-and-butter neonatology case, and let's use it to talk about readiness for discharge.

Heidi, I'm going to turn this over to you. You see these babies all the time. When a 34-weeker looks really good, looks like they're almost ready to go, from a nursing perspective, what makes you feel good about sending them home?

**Heidi**: Assessing discharge readiness in preterm infants can be challenging, but I like to separate it out into 3 buckets. The first one would be physiologic maturity. If the baby's maintaining the temp, if they have mature breathing patterns, there are not heart rate drops or apnea spells in an extended period of time and, of course, feeding. Feeding is a big one. They have to be able to take in adequate amounts by breast or bottle, but usually babies go home doing both. The second would be behavioral maturity, and that includes things like waking up for the feedings, acting hungry, some quiet alert periods—not many, but they still may have some periods of being alert—and actually crying. Crying to communicate is an important thing for babies to be able to do to try to communicate what's bothering them. The third thing would be parental readiness, and that means just confidence in basic baby care skills, bathing, dressing, feeding, understanding their infant's behavior at this particular gestational age, and what to expect over the next few weeks, and then, are the parents ready at home? Have they identified a PCP? Do they have the car seat? Do they have a safe place for the baby to sleep? And then lastly, do they have some supports, people to help them when they get home, family members, friends? It will be important to have some support systems in place before they leave the NICU.

**Dr. Smith**: I want to focus on the feeding just a little bit more, so Cuyler, I'm going to turn this to you. This baby is currently taking part of her feeds by NG because she's fatiguing. Is that a reason to hold that discharge or is that something that the family can handle at home?

**Cuyler**: This is an interesting question because whether or not to discharge home with NG support or giving that infant more time to build the endurance, the stamina—as well as the functional skills for an efficient feeding pattern—really does depend on the unit, the institution, and then, looking downstream, what community resources are in place. I'm in a level 4 NICU and we do not discharge home with NG feeds as our community is not able to provide the support necessary for families to continue with NGs at home in a safe environment. We do not have the formalized outpatient clinics that have the ability to see these infants as often as they would need to be seen for weight checks, and also to help families problem-solve, how to deliver NG feeds, what to do when things go a bit awry, and then how to slowly wean or transitioning them to full oral feeds. On our unit, we elect to wait until that infant is able to maintain their growth velocity through oral means alone.

And if we talk specifically about this little one, I can share a little bit about what we're looking for to determine whether this baby is considered a competent feeder. We go based on the definition from the Pediatric Feeding Disorder Consensus publication which was in 2019 *JPGN,* and this defines feeding skill as needing to be safe, functional and efficient. And then your feeding specialist can add to that definition by further defining what is actually efficient and functional. This infant continues to need NG support, so we know that there is a component, either of a feeding pattern or the stamina/endurance that is just not supporting full intake.

A good next step for us—as we're getting closer to that 85 percentile, but still a little bit low on how many grams we're

gaining per day, also the reliance on fortification—is we would encourage our family to room in. The primary feeder is really the feeder that we need to display competency as the infant is also displaying competency of the skill. Feeding is a dyadic occupation and even if an infant has the ability to use a coordinated suck-swallow-breathe, is able to take all of their nutrition through initiation from themselves vs initiation from the feeder, we also need the caregiver or the person that's going to be responsible for feeding this baby, to demonstrate those skills as well. Think of them as a complete unit, and skill development must be on both sides for you to truly have a competent feeding entity.

For this little one, most likely she's continued to work on building endurance and stamina, you will see that that results in discoordination of the feeding pattern. As endurance goes down, as the muscles fatigue, as our sensory response is slowed, as we're kind of basically what I call neurologically coming offline, as infants move out of optimal states of arousal, you'll see changes in the feeding pattern itself. And this is really where your feeding specialist, your OTs and your SLPs can be an asset in helping families identify when the feeding pattern is starting to convert to a more reflexive feeding pattern that is not infant-driven, that does not have power behind the suck and is no longer efficient. And once we lose efficiency and lose arousal, we also lose safety within the feeding pattern. This is where we need to step in and continue to use our supplementation support. That baby is no longer in a learning phase. They instead have moved into a rest phase, and they need support through supplementation.

A good next step is to help the family identify how the baby is eating, what is the quality of the baby nippling, and when do they start to see those changes as they have changes in state and arousal. Then, if we could support them on our units by being the primary feeder, doing all the feeds with the baby, that will really give us a true picture of are we at 75%? We may in fact actually be closer to 65%, or maybe we're closer to 95%. It depends on the interaction between those 2 primary players in feeding, which is the caregiver and the infant, and how they interact together to reach safe, efficient, and functional feeding.

Also, for this particular infant, I think it's important to pay close attention to the gestational age at birth and the current gestational age. While this is a 34-week infant, not extremely immature or premature, and also has a relatively low complexity NICU stay, we have to remember this baby is only 10 days old and within the 35th week of gestational neural maturation. At that stage, or at that age of gestation, the feeding pattern is not mature. Our baby's start with a compressive base pattern, move into variability of compression and suction development and there are multiple stages before we get to what we would consider a mature, nutritive suck pattern. I would expect that this infant continues to use suction as well as compression, which is much less efficient, that she uses short suck bursts and requires long respiratory pauses to support her intake. If we look at where she is in feeding maturation based on gestational age, she continues to be at risk if she were required to meet her nutritional needs by oral means alone. That would require the feeder to be highly skilled in how they support the infant and manage the fatigue and manage the changes in the feeding pattern that we would expect, as seen in the case study, with her moving into discoordination. Those management and support techniques, while they may seem second nature to our NICU staff, are not for families. The methods that we need to use to keep our babies safe as they're learning and maturing their feeding patterns is a specific skill set and it may not be appropriate to have that expectation of the parent, especially if this is a first-time parent, and this is the first feeding interaction that they've had with a little one.

One other point I would make is that she is low on the grams that she's gaining per day. We already know that we're at the end of where we would consider safe to be sitting for growth. The 75% to 85% of oral intake also can be concerning because if she's not well supported, I would expect that she's going to slide down to that 75th percent and may even drop lower without the supports that trained, skilled, NICU staff are currently providing.

**Dr. Smith**: Jill, I want to turn this to you. As a primary care pediatrician who's going to be following this baby as an outpatient, what information would be most helpful to you from the inpatient team and what would you like to make sure that the inpatient team has put in place before they send this baby home?

**Dr. Kasper**: I think a few things are critical to help set this baby and this family up for success. Most important is the warm hand-off. I want to hear your voice. I want to talk to you. You can tell me things that aren't going to be in the discharge summary so I can learn a little bit more about the family dynamics. I can really learn some of the things that you guys got to know in the 10 days that you had with the family because I'm really only going to have 20 minutes. I think your team, again, is excellent about doing this. I think it's critical that a family leaves the NICU with appointments in hand. I'm getting anxious about this case now because I

see feeding team in this baby's future and if that kid doesn't have an appointment with the feeding team yet, it's about to take about 4 months and asking a lot of favors to get her in with them, sorry. I think really having those conversations and the "what ifs" ahead of time can be critical. I love to see a feeding plan, and I think it's helpful, not just for me, but also for a lot of my newer colleagues too. Yes, the baby is taking fortified breast milk, what is she supposed to be doing? What does fortified breast milk mean? How many ounces of this, how many scoops of that? And then, what are the goals? The number of ounces, the frequency, and I think also looking at weight gain in terms of goals, particularly given that when access is tough babies can be seeing multiple care providers in the first couple of months and so really having documented our goals and what we should go by. I think it's helpful to spell out the corrected age. This baby is only 35½ weeks and so still a preterm baby, and spelling that out for people. And then I think, lastly, I want to know who was trained on the feeding. I think this mother lives with her parents, they're doing the driving. There's a motivated dad, but he's not in the home, so I want to know who knows what and who can help the mom at 3:00 in the morning when she's struggling.

**Dr. Smith**: That's a great answer. We're going to come back to the family in just a second. I want us to go back to thinking about a little bit of anticipatory guidance for this particular infant and this particular family. Cuyler, what would you tell this family to expect about feeding this baby at home? What are the next few days vs the next few weeks going to look like from a feeding perspective, and when should they start to worry that "she's just tired" is really something else?

**Cuyler**: I feel it's so important to have these types of conversations with families so that they have a realistic picture of what does feeding progression actually look like. Feeding progression is not linear. It's not a smooth and steady upward trajectory. Rather, it can be depicted as rolling hills that work towards that elevated place of skill development, but everything that the infant experiences during the day is going to affect their state, their arousal and their endurance in feeding. Feeding is the most complex skill that's required by the infant and it really requires medical stability and wellness in every subsystem, as well as the actual oropharyngeal skill of feeding and swallowing. It would be important to highlight the fact that dips and valleys and plateaus are normal in feeding development and our job is to provide optimal support which we would need to do through direct, one-on-one demonstration, coaching and sharing and engaging in the feeding experience, with the parent as lead, so that they can develop the skills that are needed to support that infant, depending on what has happened to that infant during the day. Did they have an ultrasound? Did they have an eye exam? Had they recently got vaccinations? Had they been weaned from oxygen? All of this will impact what we see at bedside when it comes to feeding.

At times, when an infant is needing a bit of a rest or has a small plateau or even a decline in their oral intake, families really feel responsible. They may feel that there is going to be a delay in discharge based on that 1 feeding or based on that 1 day's quantitative numbers. And it's so important that we support caregivers and help them see the big picture, and where we're going developmentally, so that they're not tempted to be a bit more aggressive at bedside, because the natural tendency is that we want to feed and nourish our babies. That's one of the primary urges that the caregiver experiences and they may get a bit more aggressive, which has a negative connotation, or you could say a bit more supportive. That, in fact, isn't giving the infant what they need at this time which may be more supplementation in that particular feed. I feel it's particularly important to engage caregivers in these discussions, to understand from their perspective how are they viewing feeding so we can be their champion and their partner as we walk the family through normal feeding development as we're working towards discharge.

One other area of education that's helpful for caregivers is to be able to identify when the baby is getting fatigued and the feed needs to be stopped, so that we can prioritize rest and recovery to prepare for the next feed vs when is there something truly problematic occurring within the feeding. If you look at some firm red flags that are perhaps a bit easier for our community to understand, you can refer to the 5-minute and the 30-minute rule. If a feeding is 5 minutes or less, we do have an issue. That is a sign of early shutdown, rapid fatigue, it may be linked to an issue with swallowing or just maintaining physiological stability. Or does that feed extend beyond 30 minutes? That is indicating that we have an inefficient pattern and we truly do need the support of either supplementation and nutrition, or we need the support of a feeding specialist if that is how a child is presenting at home. Think of the 5- and the 30-minute rule. And then I also work with families at bedside to identify the small, subtle cues that the baby is sharing. When the suck starts to change, when they get a little weakening around the oral seal, when you start to see a little bubbling or maybe even a few drops of leakage, or they need very long respiratory pauses, they are giving us those signs that

they're starting to transition into reflexive feeding in a sleep state and we need to stop the feeding; again prioritize rest and recovery and then we'd be looking for the next cues that the baby is ready to feed again. If that baby is doing short or very prolonged feeds, they often do not have good rest periods between. They may want to eat every hour, every hour-and-a-half. That snack feeding is also a sign that our babies are getting tired and they need additional supports. Working with the family on identifying those differences can really be key to their peace of mind so that they're not trying to use other strategies with the infant as well as their overall education on how to advocate for their baby after discharge, and when they need support from their PCP or subspecialties.

**Dr. Smith**: Heidi, we just heard what Cuyler had to say about expectations. What do we teach parents at the bedside to watch out for before they go home, and how do we teach them to know when their baby is getting enough?

**Heidi**: Feeding is a big issue, probably the biggest issue that these babies and their families face when they take them home. Cuyler addressed it in detail and very well. I would just add that we teach the families that all babies have some feedings that are better than others, that's normal. But if a baby has 2 poor feedings in a row, they should probably check in with the PCP. They shouldn't wait on this. Feeding is too important. Other issues of concern are excessive spit-ups or vomiting, any change in the color during the feeding, change in the baby's work of breathing, not voiding or stooling in their normal patterns. For all of these, I would suggest to the families that you would want to check in with your PCP. Basically, we teach that if something is different or there's a change in the baby's normal behaviors or their regular appearance, call your PCP. We encourage the families to trust their judgment. They know the babies better than anyone. We tell them, if you're concerned, you should call. And communication between the NICU and the PCP is very important here. As Jill said, they don't know the baby as well as we do, so if the PCP is aware of the baby's feeding history and other issues that have come up, they'll be better prepared and more able to help the parents when they do call.

**Dr. Smith**: I'm going to transition us. Jill introduced a few aspects about the family, and I think we should jump into that in a little bit more detail, mostly just focus on the infant. So just a little bit more detail about them. The mom is 24, she lives with her parents in a multigenerational home. She's in the NICU every day, learning to take care of the baby and she acknowledges that she is a little anxious and she is a little nervous. The father is a first-time father as well. He is involved, but he doesn't live in the house with the mom. He has a full-time job and so he's in the NICU as often as he can, including participating in rounds and learning the care. He is very interested in learning to help take care of the baby, but doesn't live in the same house. In addition, the mom's parents are her primary means of transportation. They're willing to drive her to the appointments, and they've been driving her to the hospital this whole time, but they're not necessarily comfortable with medical information and their ability to retain that information. As part of the discharge planning process, you have to also assess the family, what their strengths are, what their areas of vulnerability are, and where they're going to need to have a little bit more support. As we continue to think about this kind of family assessment piece, Heidi, I want to turn to you. We have a mom who doesn't drive, a dad who doesn't live with the baby, and grandparents who do drive but struggle with medical information. Who is it we teach and what will we consider successful discharge planning in this situation?

**Heidi**: I would say, first of all, communication is essential here. You need to find out what the dad and the grandparents view their role as, first. They're all going to be part of the baby's team at home, so they all need to be able to work together and know what the other one is going to be capable of doing and wants to do. I would teach everybody who is going to be providing care. Anyone who's going to be involved in the baby's care should come into the NICU. We will teach who's ever going to care for the baby, and their skills and their teaching is going to be really important because the mom is still recovering and she's trying to get her strength back from the delivery, so she'll need adequate rest and nutrition, and some supports to listen to her and to help her with caring for the baby.

**Dr. Smith**: Heidi, this mom is pretty nervous, and the grandparents are worried that they're not going to remember the information. How do you teach it in a way that sticks?

**Heidi**: First of all, you need to acknowledge that being nervous is normal, that virtually all parents who take babies home from the NICU are feeling nervous and unsure. Secondly, you need to encourage the family to spend as much time as possible in the NICU. Caring for the baby in the hospital with nurses and other supports available is the best way to build confidence, and they need to learn skills and get to know the baby's behavior. One way that we can do this is to encourage them to stay overnight if they are

interested. Some parents need more support than others. Sometimes we've had parents stay overnight more than once, but you need to talk to them about it and see where they are in their confidence and how they feel about caring for the baby. Thirdly, you need to identify again those who are caring for the baby at home, and they need to come to the NICU and they need to learn the baby's care. One idea is to have the mom teach the grandparents with the support from the NICU nurses. This helps the mom gain confidence and shows that she knows how to care for her baby. And the grandparents, coming from a different time period, may have a lot to learn about baby care that we are providing today, and having mom show them, with the back-up of the NICU nurses, shows the grandparents that this is how the baby needs to be handled and cared for. Teaching in small segments, this is really crucial, helps families not to be overwhelmed. Also, repetition. If we teach a small thing one day, we need to repeat it the next day and continue to do that. Sometimes, we have to do it multiple times until the parents feel comfortable. And then communicate. Communicate with the family. What do they feel confident about? What do they feel, or they worry about or something they're unsure of? Again, when you're involving grandparents and the dad who's not there all the time, you really need to identify what things they are comfortable with and are willing to be able to do. We have educational materials that reinforce all of our teaching. We encourage parents to use these written instructions if they don't remember something or they have questions at home. And if they run into problems, they need to consult their PCP.

**Dr. Smith**: Cuyler, Heidi just went through a lot of stuff that we do for teaching and one of the things she said was critically important is this whole feeding piece. For you, how do you assess whether this mother is genuinely ready to take on the job of feeding this infant at home?

**Cuyler**: I feel it's very important for the family to be in a position where they can own the feeding occupation in its entirety. That would include the bottle prep, the bottle cleaning, formula prep, initiating feeds, maintaining the schedule, preparing the infant for the feed, actually doing the feed, and then being able to calm and settle down that infant for protective rest. Often, rooming in is a tool that can be utilized so the caregivers are in the position to serve as the primary feeder, but they continue to have the supports of the unit around them so that if there is an issue that they're not able to address, they're able to pull in help in real time and work through a problem, and problem-solve that with the support of the NICU staff. Rooming in for at least 24, optimally 48, hours, sometimes even longer depending on the medical complexity of the baby. But for this particular case, a mom that has already said that she is anxious and she's hesitant to bring the infant home, I would recommend rooming in for at least 48 hours so we can see if, together as a team, they're able to maintain oral intake, protect rest, maintain their schedule and do that over multiple days of weight gain.

As a follow-up, families need support. Feeding in the unit and feeding at home are 2 very different scenarios. There are so many other conflicting priorities once you're back in the home environment. In this case, if she could see her PCP not only with the recommended PCP follow-up visits, but also doing more frequent weekly weights, perhaps for a longer period of time as well as being supported by any of the high-risk infant supports or community outreach programs available to her. The infant is still going to present with an immature feeding pattern typically at discharge. Most of our infants do not present with a full-term, normalized feeding pattern even once they're able to maintain their weight and grow. Consider everyone a continued support need and I think it's up to us, as NICU staff, to ensure that the coordination of care is present for this family once they leave our unit.

There are a few tools that might be helpful for this family in particular, especially if someone is anxious. I would recommend that we teach the family how to track oral intake as well as the ins and outs so that then they get a big picture of how that baby is feeding from not only feed-to-feed, but looking at them in 3-day chunks and looking at them in a week chunk so that when they go for those follow-up weights and visits with their PCP, they have data to compare it to. One low feed may be made up in the next 2 feeds when the baby has had a good rest and is stronger and more interested in eating. There's normal fluctuations in volumes that occur throughout the day. That can be particularly nerve-wracking for a new parent that is used to a baby eating a particular amount of milk every 3 hours on a very regimented program. We know that's not how full-term and typically developing infants and breastfed babies eat.

A food log can be quite an asset, as well as particular questions for her to ask her PCP when worries present themselves or concerns present themselves. Families need these question guides to make the most of their visits to their pediatrician. We only get a few minutes with our pediatricians, often, and in those few minutes they may be covering multiple topics. It's easy to forget a few key points and families can leave feeling like their questions haven't

been answered. It is very important that we teach families how to get the most out of their follow-up visits as well.

**Dr. Smith**: Jill, I want to turn it back to you just for a second. This mother is depending on her parents for transportation. Is that an important piece of information that you, as the primary care medical home provider, would want to know? And what would you like, in a perfect world, for the inpatient team to help set up for this family before they come in for their first primary care visit, and what do you do for these families who have transportation issues once they reach their primary care medical home?

**Dr. Kasper**: I think, when these families are getting ready to leave the NICU, if we simply ask them, do you have transportation to get to your appointment? I mean, they're going to be like, yeah, of course I do, right? Because they want to do whatever they can to get sent home, and they don't want to acknowledge any barriers that could get in the way. I think, here, there are so many layers. We need to know, are the grandparents going to be able to take this kid to the appointments and to drive mom and the kid? What are the grandparents' work schedules? What is their availability? Are there certain times of the day that are better for the appointments than others? I think we are really good at Boston Medical Center about using the MassHealth PT Fund, so my community wellness advocate actually will help these families set up transportation to and from my office and specialty appointments. It does take about 3 days to go through, and the family needs to call 3 days in advance, for a ride, but this is a critical, critical piece that helps reduce no-shows and just really reduces another barrier here. And then, if this mom is using formula to fortify the feeds for the baby, I want to make sure she has it. You know, what formula is she using, how is she getting it, does she have access to WIC? If it's a weekend and WIC is closed, where is she going to get that? Just some of the other social determinants of healthcare that are playing a role.

**Dr. Smith**: That's a great way to segue to a deeper discussion about transfer of care and coordination of care. Let's talk about that first primary care visit a little bit more. What makes a NICU hand-off actually helpful to you as a provider receiving this family for the first time and what are some of the common less helpful or incomplete things that you notice when a former NICU baby shows up at their medical home?

**Dr. Kasper**: I want to know a lot about this family before they're in my room. I think what often happens, particularly in chaotic discharges—not often but sometimes—is, here, take this document to your provider, particularly if a baby is born at a different hospital, and then I have zero information. I don't know a birth weight, I don't know anything about the kid. I'm relying on a tired family to get the information. So again, warm hand-off, talking to people is really, really critical here. And again, I want to see how much this kid should be taking, how often, what the growth targets are for this kid. If they're not meeting it we have a couple of stopping points for us to pause and think about what we need, what we need to do. I think it really all comes down to communication.

**Dr. Smith**: That's a good point. Thinking about communication and all of these moving parts. Who's the quarterback? Who leads this communication?

**Dr. Kasper**: It's me. That is my job. And I think it's one of the under-appreciated and frankly under-compensated for time in primary care. But so we go into primary care, right, or their medical home, we want to be the first call if something's not going right with these families, and I think we have to spell it out for some of these families too because they're leaving the NICUs with 5 appointments for 5 different specialists, some of whom they're not even sure why they're going and they're like, I think my baby's kid's eyes are fine, why do I have to go see an eye doctor? And they leave, they're overwhelmed, they don't know who to call for what. So I reduce the barrier and I say, If you don't know who to call, you just call me. I'm lucky because I run our medical home for kids who have parents with substance use disorders and through that, I have a community wellness advocate who has a cell phone who patients can call directly and text directly which, again, reduces barriers there. I'm really thankful for that because thinking about what it's like in a primary care private practice where you've got 15 minutes for this kid and, really, it's kind of just you. It's a lot to manage.

**Dr. Smith**: That *is* a lot! Heidi, at this point, they've already gotten to the pediatrician. Let's back up to before they leave the NICU. From a nursing perspective, how do you talk to the family about who they're supposed to call about what and when so they're not calling the NICU a month later about a rash?

**Heidi**: That's an interesting question as well, and families are getting a lot of information so they may be a little overwhelmed. But first, we need to identify who the community supports are going to be. Who the PCP is, is there a VNA, are they going to be in early intervention, is

there a pediatric specialist that they're going to see? And we need to educate the family on the role of each of these. Why are they going there, what can they do, what can't they do? For most families, the first call will be the PCP. They should be able to direct them if they're not directly able to help them, but most of the time they can. We tell parents that they can call the NICU during the first few days or up to a week or so at home. We do make sure that they understand that we can't give medical information, however they can call us and we can help them sort out who they should call. Is this important and they should go to the hospital or is this a PCP question or is it something about formula and they've got enough to last them through the day, through the night, and they can address that tomorrow? We do send the families home with a list of all of those community supports that the baby will be involved with and we make sure they have that contact information so that if they have a question about the baby's development, that's not something that probably needs to be addressed immediately, they can talk to the early intervention provider that's coming to their home once a week, or something like that.

**Dr. Smith**: Cuyler, I want to turn it to you because you're a community provider. What's the role of a feeding specialist in this kind of communication piece of things?

**Cuyler**: It is the responsibility of the feeding specialist in the unit to paint a very clear, functional picture of how the dyad is executing a feeding. Important pieces to include in our discharge planning paperwork, so that it's able to be interpreted and absorbed by the PCP or perhaps a feeding specialist that's going to follow in the community, is first defining the feeding pattern. It's very important for people to understand how this baby was eating in the NICU so they can compare it to how they're eating after discharge. That's what brings up the red flags and helps us know if they're continuing to improve their feeding pattern. That is the qualitative and quantitating description of the feeding pattern, nutritive, non-nutritive, sucks per burst, respiratory pauses, integration and then very importantly also including what supports were needed in order for that baby to feed safely and efficiently. This is the nipple flow, it's the positioning, it's whether pacing is needed and, if so, what type of pacing and what counts, as well as bottle mechanics.

The third piece is what supports are needed on the other side of the coin which are what supports are needed for the caregiver and the family? What type of coaching strategies were used? How do they prefer to learn? How do they prefer to approach their infant? And then, how all of those supports came together in a very clear and concise written feeding plan. The last piece are any risk factors that you may have identified in the NICU that are important to communicate to the PCP. Some infants are higher risk than others and it depends on all the factors that we talked about so far. Please also include that risk qualification so that our community providers know where they need to be investing more time and attention.

**Dr. Smith**: This has been a really wonderful discussion, and this is kind of a bread-and-butter NICU patient. It's relatively straightforward. It's the bulk of the kids that we see in the NICU, not a lot of problems, stable family and we talked a little bit about discharge readiness, both the assessment of the infant's physiology and the family's technical and emotional readiness for discharge and assessment of what their strengths are, what areas where they're vulnerable, and what areas where they're going to need support to make sure that there's a safety net in place and to make sure that there's a smooth transition between being in the hospital and being home. In closing, I want each of you to give 1 or 2 sentences that you'd want a clinician to take away from having this bread-and-butter kind of NICU patient that they're discharging. Jill, would you mind kicking us off?

**Dr. Kasper**: I think I always go to just pick up the phone. The more information we have, the better. I want to hear all about this family. I think too often we hone in on the stable piece and do not focus on the fact that this is still a premature baby with a first-time mom, and *that* may be more important.

**Heidi**: Well, Jill said a lot of things that I would say. Preterm babies who go home before they get to their due date may still exhibit preterm behavior, so we have to be ready for that. The feedings may fall off. The baby can get tired. Waking can be slower. We have to be aware that those things can happen. The parents will need more support as the baby transitions to home. It's a big step and they're a first-time parent and they don't know what's really going to happen at home, so the PCP needs to be prepared for frequent weight checks and check-ins with the family. And they're going to need to be ready to intervene as the family needs.

**Dr. Smith**: I actually like it when there's consistency in messaging. Great minds think alike. Speaking of great minds, Cuyler, anything that you'd like to highlight before we transition to our next case?

**Cuyler***:* I would just like to highlight how important competency of the dyad is when it comes to feeding. Our late preterm infants can be easily overlooked because they don't require as much medical support. We don't see them as being that sick. But this is a premature infant, this is a new parent, and we need competency and support to be developed within the caregiver as well as within the infant or these are our children that are going to be readmitted because they have weight faltering or are more at risk for injury or neglect because there is a discrepancy in understanding how to feed the baby or interpret behavioral signs. Don't overlook the importance of the dyad when we're defining safe, functional, and efficient feeding.

## Case 2: A Medically Complex Infant

**Dr. Smith**: For case number 2, we're going to add a little bit of medical complexity. What we won't do is the family assessment piece of it which is going to be pretty consistent, so we're going to talk about that a little bit less with the medically complicated patient, but we'll focus on having a little medical complexity.

This infant was born at 28 weeks with a birth weight of 850 g which is between the 3rd and 10th percentile. The current chronological age is 12 weeks which corrects at about 40 weeks gestation. The current weight is 2750 g which is less than the 3rd percentile. The medical history is complicated for having a simple gastroschisis at birth, also having a prolonged ileus and multiple abdominal surgeries, having BPD/chronic lung disease, electrolyte abnormalities, liver dysfunction and a history of poor growth. The surgical treatments included staged reduction of the gastroschisis with multiple operative interventions, starting with a silo placement, then a partial reduction, then a delayed abdominal closure, then a central line, and later the infant required reoperation for adhesion removal, ultimately achieving full closure after all of that. Nutritionally, the baby required TPN for about 6 weeks and is now on fortified breast milk feedings, taking about 60% orally and the remainder by NG tube. The growth has actually been surprisingly good. Baby was able to regain birth weight by day of life number 16 and then between days 10 and, between days 16 and 51, was able to gain 10 to 15 g/day. And after day 51 to currently, the baby's been gaining 15 to 20 g/day. It's actually doing surprisingly well.

In contrast to the first case, this kid is pretty medically complicated and I would say, at least in my experience with discharge planning, oftentimes no one's going to let this kid fall through the cracks. Everyone's going to be a little bit nervous, given all the things that have happened and so, as a neonatalogist you're going to be a little bit worried. But you're not the only medical provider who's caring for this baby. In addition to the nursing team and the family, you also have the surgeons and the nutritionists so there are a lot more eyes that are going to be looking at this particular type of discharge. Heidi, I want to start with you if that's okay. You've been taking care of this baby for weeks now. Compared to a late preterm who's headed home, what's different about getting this type of medically complex baby ready for discharge?

**Heidi**: This is a different situation. These parents have been in the NICU with their baby for many weeks, if not months, and they actually usually know their babies quite well, the long-term NICU families. And they're also very confident in basic baby care skills. They've been doing it for a long time, but what they're faced with now is taking the baby home with ongoing medical issues and with medical equipment. The baby has BPD so they're going to have to learn to assess the baby's respiratory status, the color and their breathing as it is normally, and then if there's a change. With the history of the gastroschisis and multiple surgeries, they will need to monitor the baby's belly. What does the belly look like and the surgical sites? The baby also will require equipment for home NG feedings. First, they will have to learn to insert the NG tube, and they are going to have to be confident in placing it. Usually, we like 2 people in the family to be able to put the NG tube in. Then they are going to have to learn about the equipment that's required to administer the feedings at home. There's a lot to learn before the baby can go home, so what you need to do really is just spread that out. Give the family time to come in, to spend time. As I said before, repeating things. When we have the medical companies come in to teach about the medical equipment, the vendors, we have them come a minimum of 2 times because we know the first time there's going to be a lot of information that just doesn't stay with the parents. We plan for 2 teaches, and if the parents need another one, we do another one. The same for inserting the NG tube. I always say the more times they insert the tube in the hospital, the more comfortable they're going to be, because the first time you do it at home is always a little scary. I would say plan ahead and give the family enough time to learn in small doses so that they can really retain the information and feel comfortable when they go home.

**Dr. Smith**: That was pretty comprehensive. Cuyler, I want to turn it to you in this case. It looks like the growth has actually been surprisingly good, even like almost unexpectedly good, given that this baby had the gastroschisis, the long TPN course and chronic lung disease

on top of all of that. Besides his recent growth, what else do we need to take into account, as we prepare this baby for discharge, from a feeding perspective?

**Cuyler**: Particularly in this case, we really need to look at how the infant is eating and what supports are required to maintain functional feeding. Just BPD alone warrants a specialized approach to feeding so that they are able to learn suck-swallow-breathe coordination and, in this case, we're adding to the complexity with his gastrointestinal complications as well as another comorbidity. And this really does set the stage for immature feeding pattern development. Often oral initiation is delayed. Oral initiation may be linked to negative GI symptoms and so it should be expected that this infant is going to require specialized techniques, whether that's positioning, pacing, he may need to use a specialized feeding system, depending on if he can develop a nutrititive pattern, and those supports often extend well beyond discharge. We need to look at the how the baby is feeding and be able to project into the future what supports are going to be needed and to ensure that, 1) caregivers have the training and, 2) the supports are available in the community, whether it's through follow-up feeding specialty, a high-risk infant program, or nutritional support. Otherwise, the baby is at high risk of having feeding compromise after discharge.

One other thought is to also consider the brain-gut connection or the establishment of the brain-gut connection. In children with gastroschisis that require TPN use vs having tolerance of being fed directly into the stomach or even into the small intestines, these infants are at risk for misinterpretation of signals from the gut. Feelings of fullness can be misinterpreted as pain, and you can end up with a functional GI condition. It's important that families are educated on the risk to interoception when it comes to feeding or how our internal responses then affect if and when and how they are going to want to engage in mealtime. A baby that does not feel well is not going to feed well.

**Dr. Smith**: That was most enlightening. Jill, I would say, coming to you with all of the things that Cuyler was just saying to us, from a medical home perspective, this infant's going to need a lot of coordination of care, like surgery, GI, nutrition, pulmonary, follow-up planning, in addition to primary care. What do you, as a primary care provider, do to keep from being overwhelmed and, as hard as it is for you, as a provider, it's got to be even harder for the families. What do you do to help and support the families in this particular instance with a complicated baby?

**Dr. Kasper**: I think, first of all, I need to pour over that discharge summary and make sure that I'm digesting it and putting everything into a care coordination note in the chart because I am not on call 365 days a year, 24 hours a day, right? I need whoever is covering for me, at any time, to be able to glance at the chart and know what's happening with this kid. Really breaking things down into number 1, the care coordination note, and updated problem list that highlights the important things. And then really just talking it through with the family, like, I know this is overwhelming, you've got 8 appointments coming up with all different people. What can we do? Like number 1, we're going to try to do what we can to cluster some of those appointments, make it easier and my community wellness advocate can help with that, thankfully. I think the other thing is just kind of being like, okay, this is a lot. This is what I need you to focus on. This baby needs to eat and needs to grow. I want you to focus on that. Things you need to call me for, if he's not eating right, if there are any problems with breathing and then, I know he had some surgeries too, so let's think about what we need to make sure what is happening with his gut, right? Signs of obstruction are things to look for. Really, I'm going to drill it down, like really highlight with the family, yes, but let's focus on *these* things.

**Dr. Smith**: That was really comprehensive and I'm thinking, at this point, they've already made it to the medical home. Let's rewind, Heidi, to go back to you, when you're getting this family ready to leave the NICU and they're looking at that long laundry list of providers and clinics and appointments and, as Jill pointed out, they may or may not even know why they're going to some of these appointments, or may not understand why they're important. What would be your approach or the strategy that you take in preparing a medically complex infant for discharge?

**Heidi**: Oh, you're right. There's a lot of appointments these medically complex babies need after discharge. We make sure that we go through the list and the parents know what specialties they're seeing and for what reason. The first appointment, for all of these disciplines, we make sure that we make that appointment. Now, some people will say, well, the parents should make it because they know their schedule, but we feel it's important for us to make that first appointment because we need to get the timing right, for one thing. Some disciplines want to see the baby sooner than others. We also feel like that's 1 less thing for new parents to worry about. If they have to go home and make 8 appointments, and feed the baby, and try to get some

sleep, I can pretty much guarantee that some of those appointments aren't going to get made. We make the appointments for them. Then they're in the system. If they need to reschedule, I tell them all the time, if you need to reschedule, here's the information, here's the phone number, you can call and reschedule but you don't have to worry about making that first appointment. It will be made for you. The other thing that's really helpful is the baby's in the system and so if they don't make it to the appointment, the provider can follow up. That baby was scheduled and they know that they didn't come. They can contact the family and see what happened, why they didn't make it. They can also contact the PCP and let them know that the baby didn't make it to that appointment so they can follow up as well. We do give them a detailed list of all the appointments and all the providers, including the dates, the times, the locations and the contact information, as I said. Now, location of the appointments is an important topic as well. Some large pediatric facilities have various locations where they can see babies. We try very hard in making the appointments to get a location as close to the family as possible because it is a lot and, as Jill pointed out, sometimes these babies don't have great transportation systems. As I say, we try to get them as close to the family as possible. If that's not possible, we explain that to the family and talk to them about helping them get transportation. How can we help you do that? Do you have friends or relatives that might be able to help you make it to this appointment? The good thing that I always tell parents is, in the beginning, you'll have a ton of appointments but those will space out as the baby grows and matures. It's not going to be forever. You might only have a couple of appointments when you get home after a couple of months. You will have seen all the specialists and some of them may not even need to follow up, but if they do, usually it's a longer period of time in between appointments.

**Dr. Smith**: It's clear why you all are such a great discharge planning team. Cuyler, from a feeding perspective, is there anything that you'd want to highlight about a complex medical case specifically?

**Cuyler**: One thing to add would be the importance of feeding specialty follow-up after discharge. This infant requires specialized techniques in order to have oral intake. Those specialized techniques have been provided by a feeding specialist, an occupational therapist or a speech language pathologist that was specific to the baby at that point in their neuromaturation. But the baby's going to continue to develop and to continue to grow and, for that skill set to continue to build, the families need support from a specialist or a professional. It is not common knowledge how infants develop the intrinsic and extrinsic control for feeding over time and we know that feeding is a quite long developmental process. I mean, in the past, we would think that kids have all of their oral skills by 3 years of age. Well, what we know now from the literature is that swallowing continues to mature past the age of 12 and our infants and our children continue to develop mealtime skills well into middle childhood. I would just like to highlight it's important to help the families establish a connection to the community so they can find a feeding specialist or a feeding team that they trust, that can continue to walk the journey well past discharge.

**Dr. Smith**: I'm going to sum it up for this phase and, with complex infants, they really represent only the minority of the infants that we see in the NICU, but they also require the most resources and attention because when it comes to discharge planning, with the infant that's medically-complex, getting this wrong can be a disaster. With that in mind, as kind of a final thought, what would be one of your biggest concerns or one of your biggest "can't miss" recommendations? Heidi, would you mind sharing yours first?

**Heidi**: Well, medically complex babies, by definition, will have many issues that need to be followed once they're at home. As I said before, education of the families about their active issues and who is going to be following the baby is crucial. Giving families their supports, adequate time to learn and feel comfortable with the equipment their baby's needs is also very important. And lastly, there must be really good communication with the PCP as the baby transitions to home.

**Dr. Kasper**: When I see babies like this, I'm worried about 2 things. I am worried about the feeding. I'm worried that they're gaining good weight, and I worry about their breathing. Particularly in respiratory season, I want to make sure everything's up-to-date, that they have their RSV prophylaxis and any others that are indicated. those are the 2 things that keep me up at night.

**Dr. Smith**: You're not the only one worried about feeding. Cuyler, I'm going to give you a chance to close us out with your thoughts about feeding.

**Cuyler**: As a closing comment, I would just like to share the perspective that participation in mealtimes may look different for this infant vs another infant, even with the same conditions. The feeding and the mealtime and the

food relationship, as we've mentioned, develops over time and is influenced by what is happening medically, what's happening in the environment, and then what happens with that event in relation to their feeder. If the baby gets sick, the baby has another complication, if there's something affecting stress in the home, all of this can affect how mealtimes evolve and look. And so I would just like to highlight the importance of focusing on positive participation in mealtimes which may not mean we're eating everything by mouth, but if we can come to the table and maintain a positive relationship with food, then we know we're supporting that family in having a lifelong eater.

**Dr. Smith**: We're going to close off this part of the case, but I want you to think about all the things that were said and all of the interventions that were mentioned and what could potentially happen if those things are not implemented, because we're going to pick this case up again in part 2 of this series Caring for NICU Graduates in the Primary Care Setting. We're going to say what happens when a baby was looking as if they were actually doing pretty well—and then they're not.

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