

A close-up photograph of a baby with Down syndrome looking up, being held by a woman. The baby has characteristic facial features and is wearing a blue and yellow patterned blanket. The woman's hair is visible on the left side of the frame. The background is a soft-focus outdoor setting with green foliage.

# Breastfeeding & Down Syndrome

A Comprehensive Guide for Mothers  
and Medical Professionals

**ELLA GRAY CULLEN, RN, CLC, EDITOR**

*Founder and Executive Director of Julia's Way,  
dedicated to reimagining life with Down syndrome*

Also Available From [www.downsyndromepregnancy.org](http://www.downsyndromepregnancy.org)

- Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome
- Del diagnóstico al nacimiento: Una guía para las mujeres embarazadas de un bebé con síndrome de Down
- Welcoming a Newborn with Down Syndrome: A New Parent's Guide to the First Month
- La bienvenida a un bebé con síndrome de Down: Una guía para nuevos padres
- Your Loved One is Having a Baby with Down Syndrome
- Coping with Loss: Down Syndrome



Down Syndrome Pregnancy

## WHAT PEOPLE ARE SAYING

*“I wish this book had been around when I was trying to figure out how to breastfeed my son. Breastfeeding & Down Syndrome will give you the best strategies to establish a breastfeeding relationship with your baby.”*

– STEPHANIE MEREDITH, Mom of Andy, co-author of *Welcoming a Newborn with Down Syndrome: A New Parent’s Guide to the First Month*

*“A much needed resource for moms, and even healthcare providers.... This book gives guidance, practical tips, and encouragement....”*

– MELANIE CROMWELL, RN, IBCLC, San Diego Breastfeeding Center

*“I am so excited for the moms that will have this amazing book as a resource. I knew from my prenatal diagnosis that it might take more work to nurse my baby with Down syndrome, but I had no idea about all of the intricacies that came into play with her other diagnoses (duodenal atresia, repaired with g-tube placement, AV canal defect, repaired through OHS). I was lucky to find Julia’s Way on Facebook, to have an amazing therapy and social support team, and of course a lactation consultant...but, it still took us 6-1/2 long months to get nutritive nursing and I can’t tell you how many times I almost gave up. I believe having this book as a resource would have saved me hours of research, struggle, and strife. A book like this will be the difference for a lot of families. I will be sharing it far and wide to support other moms in their journey to successfully breastfeeding a baby with Down syndrome.”* – LEAH, Mom of Ivy

*“Ivette could not latch onto my breast when she was born. All the nurses and doctors kept telling me this was typical with babies like her. All I wanted to do was breastfeed, yet everyone kept telling me it probably would not happen. If I’d had a resource like this book I would have had the reassurance I needed to not give up and realize my baby could do much more than others expected of her.”* – MERCEDES MURPHY, Mom of Ivette

*“I am so happy to see this book come to fruition! Having this information available not only to parents, but to professionals and caregivers that support parents will be such a huge step in the Down syndrome community!”* – JESSIE BOHLANDER, Mom of Lily

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No book can replace the expertise of a trusted medical provider. Please consult your or your baby's medical team before making any decisions that may affect your or your baby's health.

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Thank you to the ten moms who participated in this photo and to Nicole Starr, our photographer. They helped prove to the world that babies with Down syndrome can breastfeed and buoyed my vision for an organization dedicated to breastfeeding and Down syndrome.



**Moms and babies standing (from left):** Ella and Julia Grace, Michelle and Harper, Beth and Rian, Jennifer and Emily, Amy and Catherine, Cristina and Mae.

**Moms and babies sitting (from left):** Shu and Luis, Timna and Rory, Tammy and Oliver, Lynn and Cayden. Photo ©2017 Nicole Starr.



## About Our Cover Photo

We are so grateful to Jaymee and to Marie Lafranque Photography for granting permission to use their gorgeous photo on the cover of this book.

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### Jaymee & Isaiah

My son is 5 months old, and we have been exclusively breastfeeding for two months. My husband and I knew Isaiah would have Down syndrome when I was 18 weeks pregnant. Shortly after, we also found out our son would have a heart defect. When Isaiah was born, he was full term, a good weight (6 pounds 8 ounces), and his breathing was normal. The NICU team assessed him immediately after he was born, and he was given the OK to be with us at the hospital, where we had our first successful breastfeeding session. After several echocardiograms, the cardiologist informed us that Isaiah had another heart defect that they had not been aware of prenatally, and that he would need to go to the NICU for monitoring right away. Isaiah had to stay there for a week, where he was bottle fed. After the NICU stay, Isaiah couldn't latch. After several weeks of pumping, sanitizing, and multiple lactation specialist appointments, we were able to get him to latch onto my breast using a nipple shield. After another month, he was able to latch without a nipple shield! It was not an easy road for us; we had several hurdles to overcome, but I feel that all of those struggles just make me more grateful to have the experience of breastfeeding my son.





## Expert Reviewers

We are grateful to the following expert reviewers for using their experience and knowledge to help make this book a clear and engaging reference for both mothers and medical professionals.

**Dara Brodsky, MD**, Associate Professor of Pediatrics, Harvard Medical School. Director of Education, Department of Neonatology, Beth Israel Deaconess Medical Center. Editor-in-Chief, *NeoReviews*.

**David R. Fulton, MD**, Distinguished Tommy Kaplan Chair in Cardiovascular Studies. Chief, Cardiology Outpatient Services, Emeritus. Department of Cardiology, Boston Children's Hospital. Associate Professor of Pediatrics, Harvard Medical School.

**Catherine Watson Genna, BS, IBCLC**.

**Lauren Hanley, MD, IBCLC, FACOG, FABM**, Department of Obstetrics and Gynecology, Massachusetts General Hospital. Assistant Professor of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School.

**Bridget M. Hron, MD, MMSc**, Division of Gastroenterology, Hepatology & Nutrition, Boston Children's Hospital. Instructor in Pediatrics, Harvard Medical School.

**Dawn M. Kersula, MA, RN, LCCE, FACCE, IBCLC**.

**Lisa Mahoney, MD**, Attending Physician, Division of Gastroenterology, Hepatology, and Nutrition, Boston Children's Hospital.

**Nancy Mohrbacher, IBCLC, FILCA**, author of several books, including *Breastfeeding Solutions: Quick Tips for the Most Common Nursing Challenges*.

**Lori L. Overland, MS, CCC, C/NDT, CLC**.

**Gill Rapley, PhD**, Co-author of several books, including *Baby-Led Weaning: The Essential Guide to Introducing Solid Foods and Helping Your Baby to Grow Up a Happy and Confident Eater* and *Baby-led Breastfeeding: Follow Your Baby's Instincts for Relaxed and Easy Nursing*.

**Stephanie L. Santoro, MD**, Massachusetts General Hospital, Down Syndrome Program.

**Liliana Simon, MD, MS, IBCLC, FABM, FAAP**, Pediatric Intensive Care and Breastfeeding Medicine Clinical Assistant Professor, University of Maryland School of Medicine.

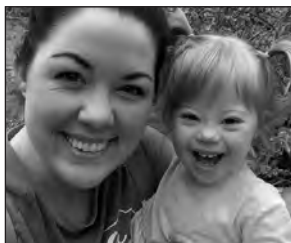


## Mom Reviewers

Thank you to the mom reviewers who ensured that this book would be a welcoming and supportive resource for those who dream of breastfeeding their babies with Down syndrome.



*Kat Bennewith*



*Cassie Bexton*



*Jessie Bohlander*



*Amy Dodson*



*Chelsea Gonzalez*



*Ann Molvik*



*Sruthi Muralidharan*



*Mercedes Murphy*



*Leah Porche*



*Lauren Rudolph*



*Sarah Sisneros*



*Sarah Christine Szuminski*



## A Note About Our Mothers' Stories

We are so grateful to all of the moms who have taken the time and energy to share their stories for this book. There is a certain reassurance in hearing the stories of women who have been where you're going and who have made it through to the other side. Our mom contributors know that, and they all have a deep desire to inspire and encourage other moms who want to breastfeed their babies with Down syndrome.

These stories are written from memories of a time that is often fraught with emotions and stress. We suggest that you take inspiration and encouragement from them, but we do not recommend that you look to them for medical advice.

Please note, we did not include any examples of mothers who breastfed from the start without any problems. This is not because those stories do not exist, but rather because the focus of our book is on mothers who are having difficulties or anticipate having difficulties with breastfeeding.

## Gender and Pronoun Use

We have chosen to alternate the pronouns used in each chapter to avoid the awkward constructions "he/she" or "they." We realize this will mean reading chapters in which the baby is referred to by a gender different from that of your baby and invite you to substitute the appropriate pronouns as you read.

*Dedicated to all of the mamas  
hoping to give their babies with Down syndrome  
the absolute best start in life*

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## Acknowledgements

When I think about the origins of this book, I think about Sarah Cullen, the Family Support Director at the Massachusetts Down Syndrome Congress (and no relation to me). When I told her about our efforts to support breastfeeding among moms of babies with Down syndrome, she asked, “So, you’re writing a book?” I was too overwhelmed even to consider a project on that scale, but the more I researched the available resources, the more I realized that a book on breastfeeding and Down syndrome, written by experts for both mothers and medical professionals, was desperately needed. As a certified lactation consultant with a passion for breastfeeding, a background in women’s health nursing, and a master’s degree in writing and publishing, I decided to try to create the resource I envisioned. Thanks to Sarah for her initial inspiration, and for her kind and compassionate support in every stage of this project.

I am still amazed when I think back to how many people responded to my email, out of the blue, asking them to be an expert author or reviewer for this book. These professionals have donated their time, expertise, and talent to support this project and to ensure that it is the best resource possible. They share my passion for breastfeeding, and in many cases, have a specific passion for helping babies with Down syndrome. I am extremely humbled and grateful to them for trusting me to shepherd this content into a book that is both accessible to mothers and instructive for medical professionals.

This book would absolutely not be where it is today without Kim Barbas, Diana Toomey, and Sruthi Muralidharan. Kim, an International Board Certified Lactation Consultant, has acted as what I call a “technical referent” for this book, and has worked diligently to help edit, direct, and keep this project on track. She was like my security blanket, and helped me ensure that the content was relevant, research-based, and easy to read. She also reassured me when I wondered if this project would ever make it to print. Diana Toomey has reviewed every word of this book. As someone outside of the medical profession, she encouraged me to simplify the language and clarify details. Sruthi, whose son, Tejas has congenital heart disease and Down syndrome, always pushed me to stay focused and relevant and to remember to write the book that WE needed when we were trying to breastfeed our babies. I am grateful to these women for their invaluable assistance.

I would also like to thank Stephanie Meredith and Nancy Iannone, authors of *Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome*, among other books, who brought their wisdom and enthusiasm to this project and replied with a hearty “Yes!” when I asked if a book about breastfeeding a child with Down syndrome would be welcome in their lineup of excellent books. They have helped me navigate this process, and I’m grateful for their patient and thoughtful feedback.

Last but not least, I would like to express my gratitude for those who supported me in my own breastfeeding journey, most especially my husband, Edward, who is the absolute best father I could have imagined for Julia Grace. I also had an excellent team of breastfeeding consultants at Beth Israel Deaconess Medical Center in Boston, and a wonderful obstetrician, Dr. Steven Ralston, who told me, “Pumping IS breastfeeding and you’re doing the best you can for your baby.” Those words of encouragement meant everything to me.

## *Dear Moms,*

If you have found your way to this book, your baby has likely received a prenatal or birth diagnosis of Down syndrome (DS). This news may or may not have changed your thoughts on breastfeeding your baby. You may have always known that you would breastfeed your baby, or maybe you've decided to try it out after learning of the exceptional benefits that breastfeeding can have, particularly for babies with DS. No matter when or how you came to the decision, you may have questions like *"Will my baby be able to breastfeed?"* or *"Is there anything I need to know about breastfeeding a baby with Down syndrome?"* Like me, you may have frantically searched the internet for positive stories of breastfeeding and DS. And like me, you may have been discouraged and disappointed. When I was pregnant with my daughter in 2016, I was scared and desperate for a resource that would guide me through the process, give me hope, and empower me in my commitment to breastfeeding my daughter.

As a former labor and delivery nurse, I knew that I would breastfeed my child, and when I found out she would have DS, it seemed CRITICAL that I breastfeed her. Reading about the many, many benefits of breastfeeding, specifically for babies with DS, reinforced my desire. I didn't really plan or prepare because I just KNEW that my baby would breastfeed, but our challenges started almost immediately. Julia Grace arrived four weeks before her due date and was taken to the NICU. For the first day or so, she was too sleepy even to try to breastfeed and then, when she could try to breastfeed, she would latch but immediately fall asleep. I started pumping just hours after she was born, but I struggled with my supply from the outset. As our days in the NICU grew in number, and we got caught up in medical complications, my dream of breastfeeding seemed further and further away.

Once we were discharged home, I was overwhelmed with the routine of pumping, feeding my daughter, and cleaning the pumping supplies on endless rotation every 2 to 3 hours. I was reluctant to seek out help because our breastfeeding relationship seemed so tenuous that I didn't know if I could stand any suggestion that I should maybe try something else. I felt that I was not really breastfeeding because I was exclusively pumping, so I never went to any breastfeeding support groups. Instead, I spent hours upon sleepless hours scouring the internet for hope, tips, tricks, information of any kind that would encourage me and help me get my daughter nursing! Eventually, I became so overwhelmed with the demands of pumping and trying to keep up my supply while learning how to be a new mom that I only tried to get my daughter to the breast every few days, and I was EXHAUSTED. There were so many times in the middle of the night that I contemplated giving up, but I was heartbroken at the thought of giving my daughter formula.

One of my turning points came when, in the middle of the night, pumping away while my daughter and husband slept peacefully, I changed the narrative in my head from *even one drop of formula is bad* to *even one drop of breast milk is good*. That took so much pressure off, and I felt proud for doing the best I could instead of beating myself up for not doing enough.

Eventually, Julia Grace did successfully breastfeed, right around 12 weeks old, just days before I returned to work. She never looked back and nursed until she was 19 months old. But I still remember how desperately I had wished for a resource like this when she was born, and that's why we are here. I started Julia's Way to help *reimagine life with Down syndrome*, and for me, that starts with breastfeeding. I had wonderful, supportive lactation consultants, but for years, mothers of babies with Down syndrome were told that they shouldn't even bother trying to breastfeed, and many mothers are still hearing that old and outdated information. Babies with Down syndrome deserve to be given a chance to breastfeed, just like any other baby, and I wanted to create a book that would fill moms like me with hope, information, and strategies to help them be successful. My goal is to rewrite the narrative that babies with Down syndrome can't breastfeed. In this, as with everything else, we must presume competence, give our babies time, and advocate for their needs. For some babies, it may take longer, but most babies with Down syndrome WILL get there.

We know that your time is valuable, and we don't intend for you to read this book cover to cover. Our robust index to allow you to look up your baby's specific condition or your specific challenge, so that you can flip to the correct page and find information and solutions. We've also done this with the mothers' stories. You can read them all, or you can use the index to find out which moms and babies faced issues like yours. The one chapter I would urge you to read from start to finish is "Preparing to Breastfeed." Whether you have a prenatal or a birth diagnosis, this chapter is a great primer.

Warmly,

**Ella Cullen, RN, CLC**

Mom of Julia Grace

Founder and Executive Director of Julia's Way, *dedicated to reimagining life with Down syndrome*

## *Dear Mothers and Medical Professionals,*

The question shouldn't be, *Why breastfeed a baby with Down syndrome?* but *Why wouldn't you breastfeed a baby with Down syndrome?* Breastfeeding is an attainable goal that has been reached by many moms and their babies with Down syndrome, even those with complicated birth and medical histories. At first, some babies with DS may need close monitoring and intervention by lactation and feeding professionals, and they may take more time to achieve exclusive breastfeeding, but the many long-term benefits make these additional efforts more than worthwhile.

Breast milk is essential for babies with Down syndrome since they are at risk for many health-related issues including heart and gastrointestinal problems, diabetes, hypothyroidism, chronic ear infections, rhinitis, sinusitis, and leukemia. Breastfeeding/breast milk can offer vital health benefits to babies with Down syndrome. Besides the many health benefits of human milk such as digestibility, absorption, immunological protection, and bacteria-fighting properties, the act of breastfeeding itself provides oral-facial exercise with every feeding, and can actually alter and improve the oral-facial development of these babies who are at risk for obstructive sleep apnea, issues with dentition, and speech delays. The American Academy of Pediatrics (AAP) affirms that “choosing to breastfeed should be considered an investment in the short- and long-term health of the infant, rather than a lifestyle choice.” In addition to the AAP, the American College of Obstetricians and Gynecologists (ACOG), the American Academy of Family Physicians (AAFP), the Centers for Disease Control (CDC), and the World Health Organization all recommend at least six months of exclusive breastfeeding. Babies with Down syndrome should not be excluded from this recommendation just because it may be more challenging, or take longer for them to learn to breastfeed. Indeed, the National Down Syndrome Society, a leading Down syndrome advocacy organization, encourages mothers to breastfeed their babies as well, due to the many benefits that these babies receive specifically from breastfeeding.

Babies with Down syndrome will reap numerous benefits from the healthful properties of breast milk and from the positive structural and functional effect of breastfeeding itself. Perhaps equally important, breastfeeding will help nourish the bond between mother and baby. It is our duty to educate all parents of babies with Down syndrome about the bountiful benefits of breastfeeding and breast milk for their sometimes vulnerable little ones. I urge you to encourage and support these mothers who choose to breastfeed their babies with DS.

Warmly,

**Jill Rabin, MS, CCC-SLP, IBCLC**

## *Dear Medical Professionals,*

Thank you for your interest in this subject and for your commitment to helping babies with Down syndrome get the best possible start in life! I encourage you to read the mothers' stories throughout this book. You may notice that a frequent theme is "the doctors (or nurses, or lactation professionals) told us we couldn't, but we did!" I point this out not to cast medical professionals in a poor light (I am a nurse myself) but to help you understand that mothers are *desperate* for *your* support, encouragement, and knowledge. You are a huge factor in your patients' success in breastfeeding. They need you to understand how deeply important breastfeeding is to their families, their values, and their children's future. Medical professionals, especially doctors, who encourage a nursing relationship not only give these babies the benefit of their mother's milk but, in some cases, can give these mothers the opportunity to accept their child more fully. Many mothers are well-bonded with their babies, regardless of diagnoses. However, some struggle with their baby's diagnosis of Down syndrome and feel unsure about how to approach this little baby that they may perceive as so very different from what they'd hoped for, dreamed of, and imagined. If this is the case, they can benefit enormously from medical professionals who encourage their breastfeeding relationship. Developing a successful nursing relationship can set the tone for the future of parent/child interactions, and allows mothers to feel empowered by giving them a concrete and measurable way to help their babies. It can also strengthen the mother/infant bond and lend a sense of normalcy to what may be a very abnormal and difficult time.

I know how important this encouragement is, having had outstanding support while my baby was in the NICU. However, I heard from many friends that discouragement from medical professionals was the reason that they didn't try to breastfeed or that they gave up before they were ready.

One further note: we have strived to make this book as evidence-based as possible so that you can rest easy knowing that you are doing what's best for your patients with the weight of the evidence behind you. We have decided not to place footnotes in the chapters of this book in order for it to be more accessible to mothers and to improve the flow of the content. However, at the end of each chapter, there is a list of selected references.

Thank you so much for taking the time to invest in learning how to support these mothers and babies. I urge you to take the information you find here, use it in your clinical practice, and share it with your colleagues. We are always seeking to improve our materials and have training programs for medical professionals in our vision for the future. Please reach out to us at [love@juliaway.org](mailto:love@juliaway.org) with any questions, suggestions, or issues.

Sincerely,

**Ella Gray Cullen, RN, CLC**, Founder and Executive Director of Julia's Way,  
*dedicated to reimagining life with Down syndrome*



## *Dear Colleagues,*

I am thrilled to introduce to you this valuable resource for new and expectant mothers of babies with Down syndrome. As you are aware, babies with Down syndrome typically have low muscle tone and, for some, this can make breastfeeding challenging. However, with proper support, most babies with Down syndrome CAN learn to breastfeed and will be able to experience all of the benefits that breastfeeding entails. As medical professionals, we have an important role to play in supporting every mother who wishes to breastfeed from the moment her baby is diagnosed with Down syndrome.

While there are not many studies of breastfeeding in babies with Down syndrome to guide us, we can learn from what has been published and from mothers who have successfully breastfed their babies. Some mothers who discontinue breastfeeding cite other illnesses or a NICU stay as a reason for stopping. Others have difficulties with latching or perceived inadequacy of milk supply. These challenges, and others, can be addressed. For example, when babies are too sick to nurse at the breast, they can usually still receive expressed milk via nasogastric tube or bottle. Mothers can learn to use a breast pump effectively to increase their milk supply and to provide expressed breast milk until their babies' health improves. Lactation consultants can help address difficulty with latching and can offer instruction on positioning and other techniques.

**To support new and expectant parents** who want to breastfeed their babies with Down syndrome, we can:

- Share written materials like this book and the brochure “Nursing and Down Syndrome: A Short Guide to Breastfeeding Your Baby,” both of which are available as a free download from Julia’s Way ([www.juliasway.org](http://www.juliasway.org)).
- Recommend online resources and support groups. A list of resources can be found in the appendix and at [www.juliasway.org/resources](http://www.juliasway.org/resources).
- Make a referral for the family to meet prenatally with a lactation consultant, if they desire.
- Help the family find support from other parents by referring them to local and national Down syndrome organizations like:
  - Down Syndrome Pregnancy [www.downsyndromepregnancy.org](http://www.downsyndromepregnancy.org)
  - Down Syndrome Diagnosis Network [www.dsdiagnosisnetwork.org](http://www.dsdiagnosisnetwork.org)
  - The National Down Syndrome Congress [www.ndscenter.org](http://www.ndscenter.org)
  - The National Down Syndrome Society [www.ndss.org](http://www.ndss.org)
- Provide them with connections to other mothers who have successfully nursed their babies with Down syndrome through local support groups or through the Down Syndrome Diagnosis Network’s online breastfeeding support group.

**After the baby is born, we can:**

- Congratulate the parents on the birth of their new baby and share their joy!
- Ensure that all recommended health screens have been performed. Please refer to the American Academy of Pediatrics Clinical Report – Health Supervision for Children with Down Syndrome for details. All newborns with Down syndrome should have:
  - a screening echocardiogram (even if there is no murmur)
  - thyroid function tests including thyroxine and thyroid stimulating hormone
  - a complete blood count to rule out transient myeloproliferative disorder (also known as transient abnormal myelopoiesis)
  - a newborn hearing screen
  - an eye exam to confirm normal red reflex (rule out cataracts)
- If there are symptoms of swallowing dysfunction, request a clinical feeding evaluation and/or modified barium swallow or flexible endoscopic evaluation of swallowing.
- Make a referral to a lactation consultant.
- Give the new mother information about, and a prescription for, an effective breast pump. Encourage her to find out if her health insurance provides coverage for a breast pump for home.

If a mother chooses not to, or is unable to breastfeed, support this decision as well, and share appropriate information and resources for feeding her baby.

I invite you to read through this book to become aware of techniques, problem-solving strategies, and resources for nursing mothers whose babies have Down syndrome. Even as a physician with more than 14 years of experience caring for babies with Down syndrome and working closely with lactation specialists, I learned a tremendous amount from this book and very much look forward to sharing it with my patients. I hope you will also find it useful and will share it widely with your patients and colleagues.

Sincerely,

**Emily Jean Davidson, MD, MPH**

Director of Prenatal Service for the Boston Children's Hospital Down Syndrome Program  
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## Preparing to Breastfeed

KIMBERLY BARBAS, RN, IBCLC • ELLA GRAY CULLEN, RN, CLC

If you find out during your pregnancy that your baby is likely to have Down syndrome (DS), you may be asking yourself, *Will I be able to breastfeed this baby? Do I need to do anything differently to breastfeed a baby with Down syndrome?* If you have searched online for guidance about breastfeeding babies with DS, you have likely found mixed information. The truth is that some babies with DS do struggle to breastfeed, especially if they have other medical complications like prematurity or a congenital heart defect. However, according to a recent Israeli study, approximately 84% of babies with DS were getting some of their intake from breastfeeding upon discharge from the hospital and 66% of babies with DS were exclusively breastfeeding. This should provide some measure of reassurance. Even if the start to your breastfeeding relationship is challenging, most babies with DS can make the transition to breastfeeding with time, patience, and the help of thoughtful professionals.

## BENEFITS OF BREASTFEEDING YOUR BABY WITH DS

Breastfeeding is important for any baby, but one could argue that babies with DS benefit more from their mothers' milk than other babies. For example, babies with Down syndrome are more likely to be born early (or *prematurely*). The benefits of breast milk for premature babies are well known, and, if your baby is born prematurely, you will be encouraged to give your baby breast milk right from the start, including *colostrum*, the first milk that your body makes. There are other health-related issues that babies with Down syndrome can sometimes face, including heart and gastrointestinal problems, hypothyroidism, chronic ear infections, rhinitis, sinusitis, and leukemia. Research has indicated that breastfeeding can help decrease the risk for all of these issues. In addition to the known health benefits of human milk such as digestibility, absorption, immune protection, and bacteria-fighting properties, the act of breastfeeding itself provides oral-facial exercise with every feeding, and can actually alter and improve the oral-facial development of these babies, which is especially important, as babies with DS are at a greater risk of obstructive sleep apnea, issues with their teeth, and speech delays.

Babies with DS often experience developmental delays and disabilities. When you breastfeed your baby, the sensory exploration of sight, hearing, smell, taste, and touch occurs many times

a day and is key to your baby's development. He gazes into your eyes, providing him with visual stimulation; you talk to him, providing auditory stimulation; and the smell of your body and breast milk, the sweet and varied taste of your breast milk, and the tactile stimulation of your bodies touching all provide further sensory stimulation to support his development.

The advice in this chapter and the other chapters in this book will help guide you and your baby toward a successful and satisfying breastfeeding relationship. Even though medical professionals have significantly advanced their understanding of the capabilities of those with Down syndrome, there is still a lot of misinformation about whether babies with DS can successfully breastfeed. As with most things in life, being informed and prepared is essential to your success and will give you the courage to speak up for your baby, if needed.

### Pro Tip



According to a recent study by Zivanit Ergaz-Shaltiel of over 400 neonates with Down syndrome, approximately 84% were receiving breast milk when they left the hospital after birth and 66% were exclusively breastfed. Even though these babies had an "increased rate of congenital anomalies and perinatal complications, most infants were discharged home in good medical condition and were exclusively breastfed." When their mothers receive the proper support and education, babies with DS are often as capable of successfully breastfeeding as their typical peers.

## HOW TO INCREASE YOUR CHANCES OF BREASTFEEDING SUCCESS

If you have time before your baby arrives, especially if you have never breastfed before, taking a breastfeeding class is a great way to get basic information on how breastfeeding works. The class instructor can also connect you to a local support network of breastfeeding professionals who will be there to help you if you have challenges after your baby arrives. Hospitals and community breastfeeding groups frequently offer classes and ongoing support. A breastfeeding class will teach you:

- How breastfeeding works
- Ways to establish a good milk supply
- How to help your baby get a good latch
- How many feedings your baby needs in 24 hours and how to know if your baby is getting enough milk
- Different positions for breastfeeding
- When and where to get help if you need it

The instructor may also help you identify any breast anatomy variations that could present challenges as you attempt to breastfeed your baby (see chapter on anatomical variations for more information). Ideally, a breastfeeding class will be a supportive, encouraging, and educational environment that will help you gain the confidence and skills to breastfeed your baby successfully.

### Develop a support network

Establishing a support network before your baby is born can ensure that you have the tools and resources at your disposal if you need help after your baby is born. There are several organizations that help new parents who are expecting a baby with Down syndrome, in addition to social media sites where you can communicate with other families. Ask your medical professional or genetics counselor for contact information for your local Down syndrome organization, or visit [www.ndscenter.org](http://www.ndscenter.org) or [www.ndss.org](http://www.ndss.org), both of which have listings of local family organizations. These local organizations should be able to connect you with moms who have breastfed their babies and who would be willing to support and encourage you through the process. By establishing your support network early on, you will have time to make connections with other families who can recommend the doctors, therapists, and lactation consultants they have used with their own children, if needed.

Consider contacting the hospital where you plan to deliver and ask to meet with their lactation consultants before you deliver. Let them know that your baby has Down syndrome and that you may require extra assistance. Ask if they have a speech-language pathologist who specializes in feeding issues of babies with low tone. In addition to ensuring there are lactation services available

at the hospital where you plan to deliver, you may want to secure lactation follow-up for when you get home, in case ongoing support and assistance are required. Some pediatricians have lactation professionals on staff, so that may be something to consider when choosing your baby's pediatrician. When looking for a lactation consultant, it may be best to seek out an International Board Certified Lactation Consultant (IBCLC), as they often have experience with a wider variety of breastfeeding challenges.

## Obtain a breast pump

Most insurance companies in the US cover the cost of a new breast pump, but it is always best to confirm this with your health insurance company before you deliver, find out what types of pumps are covered, and learn the procedure for obtaining a pump. You can then work with your obstetrician or a lactation consultant to research which pump will best fit your needs. If for any reason, your baby is separated from you after birth or you need to express your breast milk long-term, it is essential for you to have an effective electric breast pump; a fully-automatic, double electric pump with adjustable suction and cycling speed is usually the most efficient. Expressing your milk is essential to establishing and maintaining your milk supply until you know that your baby is transferring milk adequately from direct breastfeeding (see pumping chapter for more information on how to establish your supply if your baby is unable to nurse after birth).



### Pro Tip

While your patient is preparing to meet her new baby, consider doing the following:

- Discuss the importance of breast milk and how to establish a milk supply if her baby cannot nurse directly.
- Encourage your patient to investigate insurance coverage for a breast pump.
- Provide contact information for local Down syndrome resources and support. See resources section in the appendix.
- Make a referral to community breastfeeding groups, organizations, or classes.

You will not know exactly what you will need to make your breastfeeding relationship a successful one until your baby arrives, but here are some suggestions that might make the process a little easier:

- A hands-free bra, for pumping more efficiently while trying to juggle a newborn.
- Hot/cold gel packs, which have multiple uses. Use them cold to help relieve sore nipples, or apply them warm before pumping or nursing as this has been shown to encourage letdown. A warm compress or washcloth could also help encourage letdown.
- A foot stool and a nursing support pillow to make it easier to manage your baby's low tone.
- Snacks that are easy to eat, high in protein, and low in sugar. For example, protein bars, nuts, or an apple and peanut butter.

## Connecting with your Local Down Syndrome Organization

There are several hundred local and regional Down syndrome organizations in the United States and many more that exist specifically to support new and expectant families. It may be helpful to connect as early as possible to one or more of these organizations as they can often provide helpful services, including:

- Answers to many of your questions.
- Connections to local families who can act as a source of support and encouragement, including local women who have breastfed their babies and who are willing to help you through the process, if needed.
- Names of local IBCLCs who have experience with babies with Down syndrome.
- Information about local Down syndrome medical programs.
- Access to your local Down syndrome community for information on new parent socials, first call programs, and other resources.

These organizations are ready to support you and your new family, and you can engage as much or as little as you would like. Sometimes just knowing that the resources are available when you need them is enough.

The National Down Syndrome Society ([www.ndss.org](http://www.ndss.org)) and the National Down Syndrome Congress ([www.ndsccenter.org](http://www.ndsccenter.org)) are two national organizations that have links to local organizations by state, and they are an excellent place to start.



## Mom Story

### SANDRA & LEO



I was at work when the phone call from my doctor came. I wasn't worried about the test; our 20-week ultrasound hadn't shown any potential markers. So, the words over the phone shocked me: "Your test results showed a high risk for Down syndrome."

The initial shock of the diagnosis was debilitating. I was furiously angry, scared, and even remorseful. I didn't know anything about Down syndrome, and I believed it was something I wasn't willing or able to handle.

As I began my research, one of the first articles I came across discussed the benefits of breastfeeding infants with Down syndrome, particularly in the area of speech development. I was fascinated to learn that breastfeeding was linked to higher levels of muscle development for speech skills. This information was a beacon of light in the dark tunnel of my grief. Breastfeeding was something that only I could do for my baby, so it seemed the perfect answer to my guilt.

My excitement was short-lived, however. To my dismay, my research revealed many articles that discussed the difficulties mothers face in attempting to breastfeed infants with Down syndrome. My path to peace with the diagnosis was halted; again, hope was replaced with hopelessness.

In August, my brother-in-law sent me a link to a news segment about Julia's Way. Tears slid down my face as the prospect of giving this gift to my baby slowly returned to me. I explored the information on the website for Julia's Way and realized that no one could tell me what my baby and I could or couldn't do. How unfair was it for me to expect him to fail at this—or anything—before he was even born. For the first time, I realized that my baby would be just like every other baby (and perhaps even more special)!

My desire to breastfeed my baby was revived. I pored over all of the resources I could find. I attended a breastfeeding course and spoke to a lactation consultant about my fears. I stocked

*SANDRA & LEO (CONTINUED)*

up on supplies and prepared myself to pump if needed. I learned about skin-to-skin contact and its importance in establishing a breastfeeding bond between mother and baby immediately after birth. Most importantly, I began to believe that my son could do this, and I began to believe that I could, too.

As the baby's due date approached, my doctor and I discussed different options for delivery. Due to the baby's diagnosis and the fact that he had been measuring very large, my doctor suggested that we plan a c-section. I knew that this would be another roadblock for us, since the policies at our hospital would not allow skin-to-skin contact after a c-section. This time, I chose not to give up hope. I would deliver the baby in whatever manner was determined by the doctors to be safest, and we would work that much harder to achieve our breastfeeding goals if necessary. I began to pray that no matter what the circumstances, breastfeeding would work for us.

I went into labor three weeks early. My doctor was on vacation, so the on-call doctor visited with me when I arrived at the hospital to discuss my birth plan. She stated that since the baby was early, she felt that we could proceed with a vaginal delivery if that was my preference. I rejoiced between my contractions: my prayers were being answered.

Leonardo "Leo" David Green was born at 6:44 pm on September 22, 2017. After more than 90 minutes of pushing, my precious baby boy was placed directly on my bare chest, where he remained for an hour before slowly making his way down to my breast. And when I guided his tiny little chin to my nipple for the first time, I watched through my tears as my sweet boy opened his mouth and latched.

I would be lying if I said it was easy at first. My milk took several days to come in, and Leo struggled to get a strong latch to get enough milk from my breasts. But we didn't give up. We supplemented with formula for the first two days to regulate his blood sugar. We spent hours "practicing" on the breast before I would pump and bottle-feed to ensure he was receiving enough. When my milk came in, we used nipple shields while he learned a correct latch. However, by the time he was two weeks old, he was exclusively breastfeeding, and we had eliminated the nipple shield completely. He is now gaining weight, sleeping well, and is a happy and peaceful little baby.

Every mother's journey through a diagnosis of Down syndrome is different. For me, breastfeeding was the light that led me out of the dark tunnel of grief that surrounded me following the diagnosis. I love my son more than I could ever have imagined, and I thank God every day for choosing me to be his mother. I wouldn't change a thing about him; he is perfect in every single way.

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Sara Dawn breastfeeding Ademar

## Breastfeeding Your Newborn

KIMBERLY BARBAS, RN, IBCLC • ELLA GRAY CULLEN, RN, CLC

Congratulations on your new baby! What an exciting time. You have probably been anxiously awaiting this moment, and now your baby is finally here! This chapter will address a few common complications that babies with Down syndrome sometimes face but will mostly focus on how to establish a successful breastfeeding relationship with your baby.

You may have heard that there is an “ideal” way to initiate breastfeeding, but in truth, everyone’s breastfeeding journey is different. If you have breastfed multiple children, you know this is true! You may have a vision of your perfect birth and breastfeeding journey but, as with many things in life, you may have to go with the flow and adjust your expectations. If your baby is medically complex, or you or your baby have other challenges that need to be managed immediately after birth, these issues can take priority over initiating breastfeeding. If that’s the case for you or your baby, we suggest that you read through this chapter and then flip to the chapter that is relevant to your experience to get specific advice. Just remember, *as long as you are pumping to establish and maintain your supply, you have the basis for a breastfeeding relationship.*

## WHAT ARE THE BENEFITS OF SKIN-TO-SKIN CONTACT?

One of the first steps in establishing a breastfeeding relationship with your baby is frequent skin-to-skin contact (SSC), often called “kangaroo care” in the Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN). To do this, ask your baby’s medical team to place your baby directly on your chest as soon after birth as possible. SSC gets your breastfeeding hormones going and sets the stage for breastfeeding initiation. For a medically stable baby, the ideal is to remain skin-to-skin until after the first breastfeeding attempt. For babies with Down syndrome, this may not be possible due to pressing medical concerns; however, many moms are so overwhelmed right after birth that they don’t even ask. It never hurts to put in a request to have skin-to-skin time with your baby. Do not worry if this cannot be done immediately after birth; skin-to-skin contact can occur at any time in the newborn period, and ideally, several times a day throughout your baby’s hospital stay and after you take her home.

### Mom Tip

Place your baby skin-to-skin as much as possible during the first several days after birth. Skin-to-skin contact (SSC) has many benefits, particularly for premature babies, which is commonly the case for babies with Down syndrome. It has also been shown to get the milk-making hormones flowing! Other close family members may enjoy holding your baby skin-to-skin, and this is also beneficial to your baby. SSC will help your baby to relax, adjust to the environment outside the womb, and thrive.

During skin-to-skin contact, your baby lies on your bare chest wearing nothing but a diaper, and sometimes, a hat. SSC is encouraged because, in addition to increasing milk production and breastfeeding rates and duration, it also helps your baby to:

- Better regulate her temperature
- Gain weight
- Maintain a steady breathing and heart rate
- Decrease periods of crying
- Stabilize her blood sugar
- Bond with you

You and your baby can continue to practice SSC at home while she is learning to breastfeed—it is great for both of you! In addition to the many benefits for your baby, SSC can also help you by decreasing your risk of postpartum depression, increasing your breast milk supply, and giving you a concrete way to bond with your baby. **Oxytocin**, sometimes called the “love hormone,” is thought to be heavily involved in bonding. This hormone helps you to relax and can lower stress and anxiety. Oxytocin is released when you hold your baby skin-to-skin, and when you breastfeed.

## How do I practice skin-to-skin contact safely?

While enjoying SSC with your baby, you should be sitting upright or slightly reclined, ideally at a 15- to 40-degree angle. You should never be lying flat on your back, as this could be dangerous for your baby. This position is useful when you start trying to breastfeed your baby as well. The American Academy of Pediatrics advises that practicing safe SSC requires that you do the following:

- See your baby's face.
- Ensure that your baby's mouth and nose are not covered.
- Turn your baby's head to one side.
- Keep your baby's neck straight, legs flexed, and back covered with a blanket.
- Stay awake during SSC with your baby. Your baby can sleep peacefully but it is important to place her in a safe sleeping location if you find yourself tired or dozing.



*Carolyn and her newborn enjoying skin-to-skin contact in the NICU.*

During skin-to-skin contact, your baby may root and find her way to the breast and suckle. If this is the case, you can proceed just as you would with any other newborn, monitoring her intake by keeping track of wet and soiled diapers to make sure that she is transferring enough milk. You should try to put your baby to your breast 8-12 times in a 24-hour period. Feeding your baby *on demand* (when she shows signs that she is hungry) results in a better milk supply than feeding her on a fixed schedule. It is also better for you, too, as your baby is less likely to cry. Holding your baby skin-to-skin will help you to recognize feeding cues, which is important to ensure that your baby takes in enough milk and begins to gain weight. Also remember, it is normal for babies to lose some weight after birth. Your baby will probably be weighed every 24 hours while in the hospital, with close follow-up once discharged. If your baby needs any other nutrition than your breast milk, her pediatrician will discuss this with you.

## HOW DO I MANAGE MY BABY'S LOW TONE?

Most babies with Down syndrome have some amount of *hypotonia*, also known as low muscle tone. This means that their body may need more support to stay latched to the breast and to remove milk effectively. For this reason, whatever position you choose, consider using a firm nursing pillow to help support your baby's weight. This ensures that she (and you) won't tire out too quickly. Raising your feet slightly on a footstool encourages you to sit back in your chair, which supports your lower back, and can keep your body from fatiguing as quickly. As you and your baby get better at breastfeeding you may not need to use pillows and positioning aids. The traditional breastfeeding position of mom sitting upright, cradling a baby in her arms, may not be the best position for you and your child, at least not when your baby is a newborn (to learn more and specific positions that may be helpful in breastfeeding your baby see chapter on low tone).

### Mom Tip

There are many breastfeeding smartphone apps that allow you to record your baby's feedings (how many minutes on which side, etc.), as well as the number of wet and soiled diapers. You can also track this information on a paper document, if you prefer. These records can help reassure you and your baby's medical team that your baby is indeed taking in enough breast milk.

## HOW DO I KNOW IF MY BABY IS HUNGRY?

We often associate a crying baby with a hungry baby, but crying is actually a late sign of hunger. If you can learn to recognize the cues your baby gives when she is starting to feel hungry, you can feed her before she becomes frantic or frustrated, making the likelihood of success higher. Once a baby is hungry enough to cry, especially a baby who already has difficulty nursing, she may be too upset to latch and suckle properly. It may be helpful to think of the gas tank analogy: If your baby has her hands up at her face, her tank (or belly) is empty; if her hands are at her waist, her tank is half full; if her hands are down by her side, she has a full tank. Early hunger signs or *feeding cues* can include:

- Making sucking motions with her lips
- Opening and closing her mouth
- Sticking out her tongue
- Puckering her lips
- Rooting for the breast (moving her head as if looking for something)
- Sucking on hands, toys, or clothing
- Grunting or whining sound
- Stretching or reaching out arms and legs
- Agitation or restlessness

As you get to know your new baby better, observe and make note of the behaviors she exhibits when she is hungry and what is similar about the times that you have a good feeding (early in the morning, right after a nap, etc). Learning to breastfeed is a process, and in the beginning, you may have a few good sessions and a few challenging sessions each day. As long as your baby is having an appropriate number of wet and dirty diapers, her intake should be enough (see the chart on page 20 for details). Babies with DS are at a higher risk of Hirschsprung's disease, so if your baby does not pass her first stool within 24 hours after birth, let her doctor or nurse know right away. As always, if you have any concerns about your baby's intake or output, speak with your baby's pediatrician or a lactation professional.

## HOW DO I KNOW IF MY BABY IS STRESSED WHILE NURSING?

Babies with Down syndrome may tire easily or become stressed while feeding since it can be difficult for them. It is important to recognize when your baby is upset or stressed so that you can stop your nursing session or put it on hold until your baby is more relaxed.

Signs that your baby might be feeling overwhelmed or stressed during feeding include:

- Arching her back
- Extending her arms or legs
- Splaying her fingers or toes
- Grimacing or crying
- Yawning, hiccupping, or sneezing
- Using her hands to block her face
- Gagging or spitting up
- Looking away

These behaviors do not necessarily mean it is time to stop feeding. However, they may signal that your baby is distressed and that you need to adapt or change something to make your baby more comfortable. Try some of these suggestions when your baby is showing signs of stress:

- Skin-to-skin contact. If skin-to-skin contact doesn't work, swaddle her.
- Decrease the noise and light in the room.
- Talk softly or sing to her.
- Rock her gently.
- Caress or massage her.
- Assess to make sure she is not too hot or cold.
- Change positions to give her more neck and back support.

As you get to know your baby's behaviors and habits better, it will become more obvious when she is stressed during feedings. You will learn to identify any problems quickly and make the



## The Importance of Expressing Your Milk if Your Baby Can't Nurse

If your baby is unable to nurse directly at the breast, you should begin expressing your milk within one to three hours after birth, and continue to pump every two to three hours or 8 or more times in 24 hours. Making breast milk is a supply-and-demand situation. The more your baby demands breast milk, the more milk you will make. If your baby is not able to feed effectively at the breast, or is unable to feed at all at the breast due to medical complications or other reasons, you must recreate the demand by using hand expression or a breast pump. Hand expression has been shown to be more effective than expression with a breast pump in the first few days after delivery, especially in expressing colostrum. Ongoing milk removal will stimulate milk production and will work to establish your supply for when your baby is ready to nurse directly. It is possible that you will need to pump for an extended period, for example, if your baby has a lengthy NICU stay, or if she needs to have heart surgery. You will also need to pump if your baby is not discharged from the hospital with you. Sometimes babies with DS are not fully able to breastfeed exclusively until they are three to four months of age, but many, if not most, babies with DS do get to the breast eventually. As long as you are pumping to maintain your milk supply, you have the foundation for a direct breastfeeding relationship.

changes necessary to help your baby remain calm. As you respond appropriately to your baby's stress signals, she will be more relaxed during nursing sessions, leading to a higher likelihood of a positive feeding experience for you both.

## WHAT IF MY BABY IS TOO SLEEPY TO EAT?

Low tone and medical issues can sometimes cause babies with Down syndrome to be sleepier than other babies. This means your newborn with DS may not wake up on her own to feed as frequently as necessary in the first few days or weeks of life. Your baby should wake every two to three hours, which equals eight or more feedings in a 24-hour period. Even if she does wake up to eat, she may fall asleep frequently at the breast, or tire out before finishing a feed. If your baby is sleepier than expected, ask her primary care team if, and how often, you should wake her to feed to ensure that she is getting enough nutrients to grow and thrive.

If you're following the suggestions of your baby's medical team, but your baby is still struggling to stay awake during a feeding session, consider the following actions, which may help:

- Practice skin-to-skin contact with your baby. Remove your shirt and bra and your baby's clothing (aside from a diaper) and snuggle with her on your bare chest with a blanket over her back.
- A warm baby can sometimes be overly sleepy, so consider removing any clothing, hats, or swaddling blankets.

- Give her a little stimulation! Tickle the bottom of your baby's feet to get her to wake up, or rub her back, massage her scalp, or bicycle her arms or legs.
- If your baby starts to fall asleep while nursing on one breast, consider taking a break to burp or switch her to the other side.
- Bouncing your baby lightly may also help wake her up.
- Dim the lights. This might sound counterintuitive, but a newborn can be sensitive to bright light, and dimming the lights may encourage her to open her eyes and prevent her from falling asleep again.
- Talk to your baby and make eye contact with her.
- Stroke her face with a cool, damp cloth.
- Try to dribble a little expressed breast milk on her lips to wake her up and get her interested in nursing.

## DOES MY BABY HAVE A GOOD LATCH?

The foundation of effective breastfeeding is the latch, and you may be wondering how to determine if your baby is latching properly. Your baby has a good latch if:

- She latches deeply with a wide mouth, and her lips are flipped outward (flanged).
- Her chin is pressed against your breast and her nose is not touching, or is only lightly touching, your breast.
- You may see at least some of the dark part of your breast (your areola) above your baby's top lip. If a lot of your areola is showing, she may be latched onto the tip of your nipple and will not remove milk well. This will also cause you pain if not corrected quickly.
- Your baby's cheeks are full (not sucked in or dimpled).
- She does not pop off and on throughout the session or make noisy popping/smacking sounds as if she is losing suction.
- You can see deep, rhythmic jaw movement.
- You hear subtle "puffs" of air as your baby swallows milk.
- Your baby is relaxed throughout the session. If she's fussy or restless, she may not be well latched.



Remember, an effective latch should NOT be painful! Get help if it hurts.

## The Importance of Early Intervention

Early Intervention (EI) is a program available in most states. EI provides a team of professionals who will come to your home and assess your baby for any delays. They will then work with you to come up with a plan for how best to meet your baby's needs. The EI plan is developed with extensive parental input, and you can add feeding goals, including breastfeeding goals. In many states, you do not need a doctor's referral for Early Intervention, and most services are covered by state funds to help your baby have the best possible start. Your EI team will provide services in your home (or your baby's daycare, if needed) and can help in a variety of ways. For example, an occupational or physical therapist can identify any physical or tone issues that could impact breastfeeding, including torticollis, head tilt, and body asymmetry. A physical therapist can give you tips for positioning or swaddling which will help your baby coordinate her feeding, improving her latch and endurance; an occupational therapist may have ideas about regulating or calming your baby prior to nursing, which may help her breastfeed more successfully.

It is important to get an EI evaluation as soon as possible to help your baby in developing to her full potential and to provide you with ideas for positioning, playing, and feeding. In most states, services are provided until age 3.

## HOW DO I KNOW MY BABY IS GETTING ENOUGH BREAST MILK?

You may be wondering how you can tell if your baby is effectively breastfeeding. Look for these signs that your baby has latched well and is effectively sucking and swallowing. Your baby should start with rapid sucking (two or more sucks per second) and then have a slower, more rhythmic sucking pattern (approximately one suck per second). If your baby has a sucking pattern other than this, her sucking may be ineffective, and you should consult an IBCLC. If you are concerned for any reason that your baby is not getting enough to eat, or if she is not having enough wet or soiled diapers each day, contact her pediatrician or a lactation consultant as soon as possible for evaluation. Massage and compress your breasts before, during, and after a feeding to get a sense of what they feel like full, partially empty, and empty. This is a simple way to check if your baby has really drained your breast at a feeding or if she has, for example, gotten too tired to effectively suckle mid-session. If you feel as if your baby has not fully drained your breasts, it is essential that you pump after each feeding in order to keep your milk supply up (see pumping chapter for more details). This is particularly critical in the first 10 days after your baby is born, as this is the time that your breast milk supply is being established. Leaving milk in your breasts signals the breast to decrease production, and may ultimately cause you to have less milk than your baby needs.

The following are signs of good breast milk intake:

- Your baby feeds with a rhythmic suckling pattern (a one-to-one suck/swallow ratio) for a sustained period of time. How long your baby feeds will vary with your milk flow and supply and how efficiently she nurses.
- You hear or see swallowing at the breast.
- After a feeding, your baby appears satiated and relaxed, not tense.
- Your baby sleeps well between feeds for about two hours and does not wake up soon after feeding looking for more to eat (generally within less than an hour).
- Your newborn baby should have six or more wet diapers and three or more soft yellow poops every day.
- Your breasts feel softer after a feeding.

## A note on cluster feedings

Many babies go through growth spurts, during which they seem to want to feed all the time for a day or two. Other babies tend to have a few hours each day where they want to feed frequently, commonly in the evening hours. This is called “cluster feeding.” These times of frequent feeding are normal and do not necessarily mean that you do not have enough milk. If your infant is gaining weight, showing some or all of the above signs of good latch and milk intake, and is having adequate wet and poopy diapers each day, it is likely that she is getting plenty of milk. However, you should always address any concerns with a lactation consultant or your child’s pediatrician.

## WHAT SHOULD I DO IF MY BABY IS NOT GETTING ENOUGH TO EAT?

If your baby is not gaining weight and is not having enough urine and stool output (six or more wet diapers and at least three poopy diapers in a 24-hour period), then she may not be getting enough to eat. Healthy newborns should gain weight at a rate of 25-30 grams, or about one ounce, per day. Sometimes babies with DS can be slower to gain weight, and may only gain 15 grams, or half an ounce, a day. The Centers for Disease Control (CDC) has recognized this and has developed growth charts specifically for children with Down syndrome. Ensure that your baby’s doctor is recording your baby’s weight and height on these charts (see the appendix for a copy of these charts).

### Pro Tip



Be sure that you are using the CDC growth charts specifically for babies with Down syndrome. See the appendix for copies of these charts or download them from [www.cdc.gov](http://www.cdc.gov). An online percentile calculator based on these charts can be found at [www.peditools.org](http://www.peditools.org).

If your baby is being charted on the CDC charts specifically for babies with DS but still is not growing as expected, or is not transferring enough milk at each feeding, then her doctor may suggest supplementing her feedings. Bottle feeding is the most common recommendation, but you can also try supplementing with an oral syringe, small soft cup, or spoon, or you can try feeding her with a small tube attached to your finger in the first days or hours of her life. You may prefer to try these alternative feeding methods instead of a bottle while your baby is learning to breastfeed in order to avoid *nipple confusion*, or having your baby develop a preference for bottles. Be sure to ask your nurse or lactation consultant to teach you the proper way to use an alternative feeding method. Keep in mind, some of these supplementation methods may not be appropriate if your baby is very sleepy, has certain medical issues, or has suck/swallow concerns.

In many NICUs these alternative methods of feeding are not supported. There is a common perception that bottle feeding is less taxing than breastfeeding for your baby because bottle feeding typically takes less time for a baby; however, there is no research to support this. Often a combination of practicing at the breast followed by some supplementation is needed until breastfeeding is more established. Many babies are able to transition to breastfeeding after using a bottle to supplement, and will go back and forth between breast and bottle with ease.

### Pro Tip



Breastfeeding takes longer than bottle feeding because infants regulate the pace of breastfeeding and interact more with their mothers. Studies comparing oxygen saturations during breastfeeding and bottle feeding have been conducted in both preterm infants and infants with congenital heart disease. Oxygen saturations were maintained at higher and less variable levels during breastfeeding and remained higher after feeds. Additionally, breastfed infants demonstrated more physiologic stability and less apnea and bradycardia compared to bottle-fed infants. In contrast, oxygen levels declined during bottle feeding and required more time post feeding to recover to baseline.

Medical professionals may need to monitor your baby's intake carefully. Many doctors and nurses prefer to measure intake by giving milk by bottle so they can measure the exact number of ounces a baby takes. However, this is not the only way to monitor intake. *Pre-* and *post-weights*, also called *test weights*, are a perfectly acceptable way to monitor milk intake from breastfeeding (see sidebar to properly calculate intake with test weights).

If there is concern about your baby not gaining weight despite supplementation or other interventions, her medical team may suggest that she needs a nasogastric (NG) tube because her oral feeds are not providing her with enough nutrition to grow or prepare for a procedure, such as heart surgery. An NG tube can be an excellent way to help your baby get "free calories" and help make her strong enough to feed at the breast.

Babies who have NG tubes have an excellent chance of getting to the breast after they are older and stronger. See chapter on tube feedings if you are trying to make this decision for your baby.

If your baby needs more calories than she is getting at the breast, and if you can express enough milk, you can supplement with the fat from your own breast milk. To increase your baby's calorie intake with your own breast milk, place your expressed milk in the refrigerator, and allow the fat to rise to the top. After a day or so, skim the cream layer off with a spoon and then add the cream to your baby's supplemental feedings. Gently swirl to incorporate this cream into your milk. This cream layer is very rich in calories and may promote weight gain (see chapter on heart conditions for details on how to increase your baby's calories with your own breast milk).

If supplementing with your own breast milk is not an option for your baby, additional calories can also be added to your breast milk using formula powders or oils. This should only be done with a proper recipe from your pediatrician or a clinical dietitian.

Even if your baby needs to take nutrition from a bottle, NG tube, or other supplementation method, you can still have a successful breastfeeding relationship. You can practice breastfeeding while your baby is receiving nutrition from an NG tube to help her prepare to receive all of her nutrition at the breast. Any time spent breastfeeding allows her to practice suckling and will help her learn to associate the breast with a full belly. This is a great way to start if your baby has difficulty breastfeeding immediately after birth. You can also attempt to breastfeed, and then, if your baby gets tired, you can finish feeding her with your pumped milk.

### Pro Tip










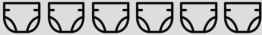






Consider using **test weights** or **pre- and post-feed** weights for mothers who are committed to breastfeeding their babies. Use a scale that is accurate within two grams. One test weight often does not give enough information, so 24 hours of test weights is better at estimating milk transfer. See sidebar on test weights for more information.

### Measuring Intake in a Breastfed Baby

Test weights, also called **pre- and post-weights**, have been studied as a way to estimate how much milk a baby has transferred from the breast. With this method your baby will be weighed immediately before and then immediately after feeding at the breast, under the exact same conditions (including the same clothes and the same diaper). The difference in weight is a good indicator of how much milk your baby took in, and can provide guidance as to how much supplementation might be needed. It is important to monitor test weights for at least 24 hours to get a more accurate assessment of breast milk intake over the course of a full day, as one or two measurements may not provide an adequate picture.

## Guidelines for Nursing Mothers

Your Baby's Age	1 WEEK							2 WEEKS	3 WEEKS
	1 DAY	2 DAYS	3 DAYS	4 DAYS	5 DAYS	6 DAYS	7 DAYS		
How Often Should Your Baby Nurse?	 <p>At least 8 times in a 24 hour period Your baby's suck should be strong and steady, with frequent swallowing.</p>								
Your Baby's Tummy Size	 cherry		 walnut		 apricot		 egg		
Wet Diapers: How Many and How Wet? Over 24 hours, your baby should have at least:	 1	 2	 3	 4	 6 with pale or clear urine				
Soiled Diapers: Number and Color of Stools Over 24 hours, your baby should have at least:	 1 to 2 BLACK OR DARK GREEN		 3 BROWN, GREEN, OR YELLOW		 3 large, soft, and seedy YELLOW, at least a quarter size or bigger				
Your Baby's Weight	Most babies lose a bit of weight in the first 3 days after birth.			 From day 4 onward, most babies gain ½ to 1 ounce a day (4-7 ounces or more each week).					
Other signs	<p>Your baby should have a strong cry, move actively, and wake easily. A well fed newborn will usually sleep after eating. Your breasts feel softer and less full after breastfeeding.</p>								

It is important to advocate for your baby and your breastfeeding relationship, but sometimes, medical concerns take priority. It may provide comfort to know that babies with Down syndrome occasionally hit bumps in the road to breastfeeding, yet many go on to overcome them. Even babies who could not nurse for months due to medical or other issues have been able to establish breastfeeding later. As long as you are pumping to maintain your supply, you have the ability to develop a successful breastfeeding relationship when your baby is ready. The mothers' stories at the end of each chapter are a good place to get inspiration and reassurance if your baby is having a difficult time getting to breast.

## I'M TAKING MY BABY HOME! NOW WHAT?

To continue close monitoring of your baby's progress, your pediatrician will schedule a follow-up appointment within two to three days of your baby's discharge from the hospital, and additional weight checks as needed until her weight gain is stable. Your baby's doctor may also arrange for a visiting nurse to come to your home. This nurse can weigh your baby and provide additional support for newborn care and breastfeeding. However, if you are concerned about your baby's weight, and your baby's doctor has not mentioned a visiting nurse, consider requesting a referral.

If breastfeeding is a concern, request a referral for an IBCLC, either to visit your home or to see you in an office setting. An IBCLC can assess your breastfeeding relationship, help get your baby to breast, and ensure that you know how to preserve your breast milk supply until your baby is ready to nurse full time. Your medical insurance may cover the cost of an IBCLC. However, if the cost of an IBCLC is prohibitive, ask your baby's pediatrician if they have a lactation consultant on staff. Your local hospital or community organizations may have breastfeeding support available on a free or donation basis.

Taking your baby home is an exciting milestone in the life of your new family. You may find breastfeeding your infant at home, without the demands and schedule of the hospital, to be easier and to feel more natural. As you work to establish a successful breastfeeding relationship, continue to practice skin-to-skin contact with your baby as often as possible. ***Baby wearing*** is an easy way to do this. There are several types of carriers that allow you to hold your baby snugly against your bare skin while leaving your hands free. Babies usually love being carried close to their mother's bodies, and this can be a simple and easy way to soothe and bond with your baby.

As mentioned previously, if your baby is having a difficult time getting to breast, you will have to pump to establish and maintain your milk supply. It can be a challenge to establish your supply when your baby is not able to nurse directly or if she has a weak or ineffective suck.



If needed, you can talk to your lactation consultant about dietary and natural ways to enhance your milk production. Remember that these methods do not work in isolation and still require frequent and consistent milk removal, which is usually most effective with a double electric breast pump (see pumping chapter for more advice and details regarding how to establish your supply when pumping).

In addition to practicing skin-to-skin contact and breastfeeding skills, it is important to work on tummy time with your baby. Often when mothers have feeding difficulties with their babies, they have less time to practice placing their babies on their tummy. However, frequent tummy time exposure is critical and will improve your baby's trunk, shoulder, and back strength resulting in improved jaw and tongue function for feeding. You can even practice skin-to-skin contact and tummy time together by lying on your back and having your baby on your bare belly or chest (similar to the natural or laid-back breastfeeding position). Hold onto your baby securely and talk or sing to her. Often babies will lift their heads to see their mommy's face, helping them develop head control, and making them stronger, as described above.



### Pro Tip

As you prepare to discharge this breastfeeding family, consider the following to prepare them for success:

- Pediatrician appointment within 2-3 days of discharge.
- Referrals to a Visiting Nurse Association and to Early Intervention.
- Resource list for community lactation support services.
- Referral to an International Board Certified Lactation Consultant, if necessary.
- Contact information for the local Down syndrome support organizations and the closest Down syndrome medical program. See appendix for links to these programs and organizations.
- A discharge summary and detailed feeding plan that the family understands, and contact information for whom to call with questions.
- A double electric breast pump for home use, if needed.

## Mom Story

### DANA & EMMA



When I was 10 weeks pregnant, I received an email that changed our family's world: Genetic testing showed that we were having a girl and that she had a 99.99% chance of being born with Down syndrome. At that moment of shock, my one plea to God was that I would be able to breastfeed my daughter. I had just stopped nursing my 15-month-old son, and I already missed the warm snuggles. I didn't know at the time how much it would benefit our daughter to breastfeed, nor how many doctors would tell me that she probably wouldn't be able to breastfeed because of her diagnosis.

Shortly after her Down syndrome diagnosis, we learned that, like 50% of all children with DS, she would also have a congenital heart defect. I kept praying; I was desperate for a way to connect with my daughter. I was already terrified that I wouldn't be able to love her because I assumed she would be different.

Much to my surprise, Emma arrived four weeks early with not just one, but three major heart defects, and yes, Down syndrome. And much to my delight, she successfully breastfed within one minute after birth. I was amazed, and I fell madly in love with my little girl. I thought I knew everything about her because of what the doctors had told me. But right out of the gate, she showed me that she would exceed my expectations at every turn. My Emma nursed exclusively through a two-week NICU stay, two complicated cardiac catheterizations, and major open-heart surgery.

Her occupational therapists believe that nursing has improved her tongue thrust, a condition that is common for babies with Down syndrome. Thanks to breastfeeding, my daughter has strengthened the mouth muscles that will increase her tongue control and improve her speech. More importantly, breastfeeding has created our bond and taught me NEVER to limit my daughter again.

## Mom Story

### JENNIFER & JULIANNA



She won't be able to go to the same preschool as Jack... She won't be able to go to dance or music class... She won't be able to say, "I love Mommy" until she's school-aged... She won't look like me, and we won't be able to breastfeed.

These are all the racing and grief-filled thoughts I remember having as I stood in my kitchen on that hot July day. I can picture myself staring out the back window as the doctor informed me that my daughter would be born with Down syndrome. I hung up the phone and spent the rest of the day in tears. I left the next day for a family

beach vacation. I had a 2½-year-old son who had just weaned off the breast the month before. I remember sitting on the beach staring at the ocean or on the porch picking at the white wicker chair, feeling such tremendous loss.

After the trip, my husband and I went to the doctor for an ultrasound. As I turned to look at the fuzzy depiction of my little girl, I could very clearly make out that she was sucking on her hand. The doctor even commented, "Wow, she is really going to town on that hand!" In that moment, I felt a surge of pride, empowerment, and hope. It was the first of many moments that my daughter and I would share once I had full faith that together we could accomplish so much. All of the limitations I was so fearful of seemed to melt away, and when the doctor left the room, I whispered aloud, "We got this, baby."

I had nursed Jack for 2½ years, so I didn't think I needed to read more books about breastfeeding, but I did want to read specifically about breastfeeding a child with Down syndrome. I looked in my library of books about breastfeeding and did find a sentence or maybe a small blurb about low muscle tone and how the tongue could get in the way. Most everything I read was discouraging, but I held on to the image of that tiny baby on the ultrasound sucking so hard on her hand.

*JENNIFER & JULIANNA (CONTINUED)*

By the time Julianna was born on that snowy December day, I was so ready to be her mom. It was a planned cesarean since my first birth was an emergency c-section. I felt a tremendous amount of peace come over me. I couldn't wait to see her, to hold her, and to bond with her in the special way that only I could.

The doctors and nurses were seemingly respectful at first with my decision not to use formula, but once we were settled in the room, things changed. The doctors and nurses began to request that I supplement with formula. When I questioned them as to why, they said that children with Down syndrome often struggle with breastfeeding, or that she needs all the nutrients she can get to thrive. I refused formula, and we persisted.

I am so grateful that I had Jack first and knew what I was doing. I think I might have been convinced to feed Julianna formula if she had been my first baby. Breastfeeding was a very familiar dance. There was nothing strange or drastically different in the process of breastfeeding her. The only thing I noticed was that she would fall asleep while feeding more often than Jack did, so I learned to tickle her feet or gently tap her cheek to keep her awake. When we went home, and I was feeling confident and comforted that this very basic and instinctual process felt normal. Maybe being a mom of a child with special needs wouldn't be as foreign as I had thought it would be.

Two weeks later, we wound up in the emergency room due to very low body temperature and low blood sugar, and Julianna was admitted to the hospital. She had to go in the incubator to keep her body warm. This meant I could take her out to feed her, but she had to be promptly returned to the clear little box. I sat by her side and did my job nursing her on demand for a week. Doctors came in and told me I NEEDED to give her formula because there was no way she was getting enough breast milk. Looking at my tiny baby in the incubator with all the tubes connected to her, and hearing the scary words of the doctors like "failure to thrive," I finally gave in and allowed a bottle. I reluctantly fed her the bottle and the formula gushed all over her face and all over me. It seemed to me that her suck was so strong that the milk was coming out too fast for her.

We were there over the New Year holiday, so the lactation consultant was not able to see us until a couple of days into our stay. She was a lovely woman, and the first thing she did was watch me breastfeed. No one at the hospital had asked to do that until then. I was overjoyed and a little startled when she yelled, "This baby nurses beautifully!" No one ever suggested a bottle after that. Julianna and I nursed beautifully for 2½ years, and the whole experience continues to be a reminder that limitations and low expectations have no place in our lives. "We got this, baby."

## Mom Story

### NICOLE & NAIMA



I am a mother of three amazing daughters who are 17, 14, and 2 years old. My youngest, Naima, was born with Down syndrome. We received a possible Down syndrome diagnosis during my first trimester of pregnancy. It was unexpected and scary. Fear immediately took me under. I felt so much pressure to be strong, but I also felt so unsure of myself. I had no idea what it would be like to have a child with Down syndrome.

My husband and I immediately began Googling, which was a terrible idea. We came across so much negative information online. I read articles on how difficult it is to breastfeed a baby with Down syndrome due to low muscle tone and a larger tongue. I was so sad at the idea that I wouldn't be able to breastfeed my third child. I had breastfed my oldest daughter for a year and my second daughter for six months. I did more research

and was convinced that I would need a supplemental nurser to breastfeed Naima, although that turned out not to be the case.

Naima was born about two weeks early due to an excess of amniotic fluid. She stayed in the NICU for five days. This was one of the hardest things I've experienced. I made my husband stay by her side in the NICU the whole first night. I was completely alone in my hospital room, and all I could think about was feeding my baby. So, I started pumping. For the first few days in the NICU, I pumped, and Naima was bottle-fed. The nurses insisted that we give her my milk in a bottle because they needed to know exactly how much she was taking in. On the third day, I finally said "No!" I told them that I was going to breastfeed my baby and that they could weigh her before and after. It took me a while, but I successfully advocated for my baby and myself. When the nurses and lactation specialist observed me nursing Naima, they were very impressed and seemed almost shocked at how well she latched on to my breast.

Breastfeeding Naima has been both amazing and challenging. Not because she has Down syndrome, but because breastfeeding is hard. Yes, it is beautiful, but it is also exhausting, painful, and overwhelming at times. I think this is a common experience for all mothers, not just mothers of babies with Down syndrome. Every mother needs support and encouragement to be successful at breastfeeding.

Don't let anyone tell you that your baby can't breastfeed due to a diagnosis. Just try. It may be difficult, but it will absolutely be worth it in so many ways. I didn't know that breastfeeding would

*NICOLE & NAIMA (CONTINUED)*

actually help Naima strengthen the muscles around her mouth and help with speech until several months after she was born.

I exclusively breastfed Naima until we introduced solids when she was 9 months old and breastfed her for a total of 22 months. I am so proud of myself! I was determined to breastfeed Naima; I believed I could—and I did!

## Mom Story

### ASHLEY & PABLO



I was never told that Pablo couldn't breastfeed, but I remember very clearly that no one ever told me that he **COULD**. He was diagnosed at birth, so I had done no formal research. I had already nursed two babies for a year each and thought I could do the same with Pablo. However, Pablo wouldn't latch and had trouble with his suck/swallow coordination. He coughed and sputtered when he tried to nurse, problems that he didn't have while drinking from a bottle.

I was discharged from the hospital but continued to make appointments with lactation consultants. They were very kind and helped us as best they could, but I had the feeling that they didn't have much experience with babies with Down syndrome. They never suggested a nipple shield or any other device that might have helped Pablo latch and nurse more successfully.

So, we struggled together for two entire months. At every single feeding, I would offer him my breast. Many times, I would pump first so that my letdown would not overwhelm him, nurse him until he got tired, then I would give him a bottle and pump again. The consultants suggested that I continue to pump; I had so much milk that I filled two large coolers to donate!

Finally, when Pablo was two months old, I ordered several different nipple shields online, and he quickly caught on! I nursed with a nipple shield for a month or so, then one day I tried without, and he was successful! As a stay-at-home-mom, I was able to nurse him for two years. I remember feeling so frustrated that because of the stigma of nipple shields, we were unsuccessful for longer than we needed to be.

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*Carolyn and Quentin*

## Anatomical Variations

JILL RABIN, IBCLC, SLP

While breastfeeding is a natural and daily occurrence, certain structural or anatomical differences for either you or your baby could make breastfeeding more challenging, even without a diagnosis of Down syndrome (DS). If your baby is having difficulty breastfeeding, request that his medical team perform a full assessment and ensure that any anatomical issues are treated by appropriate specialists. It should never be assumed that your baby cannot breastfeed simply due to a diagnosis of Down syndrome.

This chapter lists a variety of anatomical obstacles in case you or your baby is diagnosed with any of these challenges. This chapter is not meant to alarm you but should be used as a reference if your baby is having difficulty breastfeeding, or if you or your baby experience any of these possible complications. Awareness of any potential obstacles can guide you in seeking prompt assessment and intervention from a healthcare provider or an International Board Certified Lactation Consultant (IBCLC), which can lead to a more successful breastfeeding relationship.

## ASSESSING YOUR ANATOMY

A prenatal consultation with an IBCLC can help identify any potential challenges right from the start. At this appointment, your IBCLC will review your medical history, assess your breast anatomy, and discuss how any previous breast surgeries or medical issues may impact your breastfeeding relationship with your baby. In addition to assessing any structural or medical issues, your IBCLC can suggest other ways to prepare for breastfeeding before your baby is born by:

- Discussing different types of breast pumps, which type may be best for your situation, and what your insurance covers.
- Connecting you with other mothers who have breastfed their babies with DS..
- Referring you to specialists like a speech-language pathologist (SLP or speech therapist), gastroenterologist (GI doctor), or otolaryngologist (ENT or ear, nose, and throat doctor), who have worked with babies with DS and breastfeeding, so you can have them in place should you need them.
- Helping you prepare for what to expect after your baby is born.

### Possible maternal complications

While it is difficult to predict what your baby's feeding and medical situation will be after he is born, we can assess and address any challenges you may have before you deliver. Your lactation consultant will assess your breast and nipple shape and size prior to delivery to see if there are any structural or anatomical variations that might make breastfeeding more challenging for you and your baby. Being aware of this information prior to delivery will allow you to be prepared and to have a plan of action for when your baby is born, setting you up for success.

- **Small breasts** – Having small breasts is not an indication of how much milk you will make. However, your breasts should grow during pregnancy. If you have not noticed any changes in your breasts, please mention this to your lactation consultant as this may be a sign of how much *glandular*, or milk-making, tissue your breasts have. If you have very small breasts your lactation consultant may have ideas for positioning to help pull your baby closer to you, allowing him to achieve an effective latch. Positions that might help include cross-cradle, modified football, side-lying, or use of the *natural breastfeeding* method, which relies on the normal reflexes of the newborn to move his body towards the breast, find the nipple, and self-attach. You can also try the U-shaped hand position, a variation of the C-hold hand position, where you support your breast tissue from underneath, compressing your breast vertically by creating a U shape with your hand to help the baby latch.

- **Large breasts** – Large breasts may be challenging for both you and your baby. When milk comes in, the breast is heavier than usual, and supporting it during breastfeeding may quickly fatigue your arm and hand. The weight of a large breast may also tire out a newborn or cause the breast to fall out of your baby’s mouth if it is not well supported. Here are some options to try to help your baby manage a large breast:
  - **Positioning your breasts:** Roll up a small blanket or hand towel, lift your breast, and place it under your breast at the rib cage. This will support and lift the breast, taking the weight off your hand and your baby’s jaw and neck.
  - **Positioning your baby:** Nursing your baby in a side-lying or laid-back position, or using the football hold, will allow you to position him away from the weight of your breast.
  - **Positioning your hands:** Use your hand to form a C shape with your breast placed in the palm of your hand, your four fingers touching your rib cage below your breasts, and your thumb positioned gently on top of your breast. Take care not to block your areola with your fingers. This sandwiching your breast helps your baby to latch onto more breast tissue and allows you to control the movement of your breast, directing your nipple towards your baby’s mouth.

*C hand shape*



- **Large nipples** – Very large nipples, regardless of breast size, when matched up with a baby's small mouth can sometimes also be a challenge. If your baby is unable to get your nipple into his mouth or to latch deeply enough, it could cause damage to your nipple tips and affect milk transfer as well. Your IBCLC may suggest a nipple shield, which may help your baby to get a deeper latch. An IBCLC can also show you ways to help your baby achieve a deeper latch with the *gape* or *wide-open* mouth posture. An *asymmetrical latch* may also be helpful and is achieved with the baby's head being tilted back slightly, touching the breast first with his chin, rather than his mouth or nose. With this latch your baby should have more of the underside of the nipple and areola in his mouth. Any intervention for a large nipple may only be needed for a few weeks until your baby grows and his mouth gets bigger.
- **Flat, short, or inverted nipples** – A *flat or short nipple* is level, or almost level, with the areola. An *inverted nipple* flattens or goes inward with compression. Any of these nipple issues can make it difficult for your baby to latch deeply onto your breast. A shallow latch can lead to nipple pain and even nipple damage if not corrected. If you have a short or flat nipple, a nipple shield may make it easier for your baby to achieve and sustain a latch. If you have an inverted nipple, manual stimulation or pumping prior to nursing your baby, as well as using a nipple everter, may help to pull your nipple out. Another option are breast shells, which are worn in your bra in-between feedings and are designed to place gentle suction on your nipple to elongate flat or inverted nipples. Just because you have short, flat, or inverted nipples does not mean you cannot breastfeed. While it may complicate the breastfeeding situation initially, with the right assessment, intervention, and use of equipment when necessary, breastfeeding is usually possible.
- **Insufficient glandular tissue (IGT)** – IGT is also known as breast *hypoplasia*. Signs of IGT include widely spaced breasts, breast *asymmetry* (one breast is significantly smaller than the other), and a tubular breast shape. If you have not experienced any breast changes in your pregnancy or in the postpartum period, you may have IGT. If you have IGT, it is important to work closely with an experienced IBCLC to see if establishing a milk supply and breastfeeding your baby is possible. You may have a partial supply, and every bit of breast milk will help your baby to be strong and healthy. Breastfeeding in the first 2 hours after birth and hand expressing colostrum frequently after breastfeeding for the first few days may help you make more milk, even if you have hypoplasia.
- **Breast augmentation, reduction, or reconstruction** – All types of breast surgery or trauma have the potential to impact milk supply, but outcomes vary widely. If you have had breast reduction surgery, you may be wondering if you will be able to breastfeed your baby. This will depend on how your breast reduction surgery was done, how much milk-producing tissue and anatomy were affected, and even how long ago your procedure was done. Techniques have changed over time, and newer techniques tend to preserve more milk-producing tissue. The impact of breast augmentation or reconstruction is dependent upon presurgical

## Using a Nipple Shield • KIMBERLY BARBAS, RN, IBCLC

A nipple shield is a thin silicone device that is placed over your nipple. It can be an important tool in helping your baby latch and breastfeed successfully. Most of the time, the use of a nipple shield is a temporary tool and, once your baby gets the hang of nursing, you can usually leave the nipple shield safely behind. While using a nipple shield, it is important to track your baby's wet and stool diapers each day to ensure that he is transferring enough milk. For some babies, nipple shields can provide a helpful bridge to the breast; however, they should be used with caution. It is recommended that nipple shields be used with support and guidance from a lactation professional.

### Why use a nipple shield?

Nipple shields can be used to help your baby latch more easily, and stay on the breast, without using as much energy and effort. It can also help some babies transfer more milk with each feeding. They can also be used for:

- Flat, short, or inverted nipples
- Infants with weak or disorganized suckling, such as premature or medically complex babies
- Sore or engorged nipples
- Transitioning baby from bottle to breast, or for babies with a preference for bottles

### What is the right size nipple shield?

Choose a nipple shield that fits the base of your nipple, but also one that is not too large for your baby's mouth. If it is too big, it may not stay in place, or it may pinch your nipple when the baby compresses it. If it is too small, your baby will have trouble removing milk effectively. Your nipple should be able to be drawn into the shield, almost to the end, when the baby suckles. You can see this when the baby detaches from the breast as the nipple will still be in the shape of the shield.

### How do I put the nipple shield on?

In order to get correct placement of your nipple shield, you will need to turn the shield almost all the way inside out before centering it over your nipple and areola. Allow it to fold back into shape, creating a small amount of suction on your nipple. Make sure the shield is flush against your nipple with no gaps or puckers. Massage the breast and hand express some milk into the shield.

### How do I make sure my baby has a good latch?

A deep latch is very important when using a nipple shield. Ensure that your baby's mouth is closed around the breast with part of the areola in the mouth, not just the shaft of the nipple shield. Massage your breast to help milk flow, and listen for swallowing. If you are not sure your baby drained your breast effectively using the nipple shield, you should pump after feeding to ensure that you will continue to have an adequate milk supply.

### Cleaning your nipple shield

Wash your nipple shield with hot, soapy water after each use and allow it to air dry. Nipple shields can be sanitized in the dishwasher or in microwave steam-bags, or boiled in water for 10 minutes once per day to sterilize.

### How do I wean my baby off the nipple shield?

Some babies will only need the nipple shield for a few nursing sessions, others for a few days or weeks. Some mothers and babies will always need a nipple shield in place due to anatomy or other reasons. To wean, you can practice feeding without the nipple shield. Start the feeding without the nipple shield in place, and see if your baby will latch onto your breast. If she becomes frustrated, try again with the nipple shield on. Later in the feeding, try taking the shield off, and immediately attempting to latch your baby again. Continue to try until your baby will accept the breast without the shield in place.

breast anatomy (such as insufficient glandular tissue), type of incision(s), and amount of scar tissue. The key is early assessment and intervention by an IBCLC immediately after the birth of your baby. It will be extremely important to track your baby's output and growth to assess if he is getting enough to eat. Use of test weights to measure your baby's milk transfer at the breast, as well as tracking your baby's wet and soiled diapers, are ways to assess this (see chapter on breastfeeding your newborn for more information on how to do this).

If you are already familiar with any anatomical challenges that you may have before your baby's birth, you will be better prepared to plan for and manage those issues once your baby arrives. You can share the information gathered at your prenatal evaluation with the lactation team at your hospital to help them better assist you in establishing your breastfeeding relationship. This preparation can decrease your stress and facilitate a more successful breastfeeding relationship.



*Emiel, who has laryngomalacia and tracheomalacia, practices nursing at his mom, Alexa's, empty breast while receiving pumped milk through his nasogastric tube.*

## ASSESSING YOUR BABY

If your baby has any difficulty feeding at the breast, your IBCLC should do a thorough assessment of his structural anatomy to ensure that there are no reasons that he cannot breastfeed effectively. If your baby continues to have difficulty with breastfeeding even after working with an IBCLC, consider requesting a consultation with a speech-language pathologist (SLP) who specializes in infant feeding, also known as a feeding specialist. An SLP can do a complete assessment of your baby's oral anatomy, looking at his oral-facial tone, cheeks, jaw, palate, lips, and tongue. Your baby's feeding therapist will also assess his sucking strength and coordination. Sometimes a baby's sucking abilities appear coordinated when sucking on a finger or a pacifier however, once liquid is introduced, the baby may have more issues with coordinating the suck-swallow-breathe pattern that is critical to nursing effectively. For this reason, your baby's SLP should assess his suck while he is nursing or taking milk from a bottle.

Some things that might be assessed include:

- **Airway** – Airway issues are very common in babies with Down syndrome. Some of these issues include laryngomalacia, tracheomalacia, bronchomalacia, and laryngeal cleft. Symptoms of a possible problematic airway include *stridor*, or noisy breathing, hoarse vocal quality, and recurrent croup. Not all babies with *malacia* will have feeding/swallowing issues and sometimes the inspiratory stridor is alarming to parents but doesn't affect the baby. However, swallowing should always be assessed in babies with malacia because *dysphagia*, difficulty or discomfort in swallowing, frequently occurs together with this diagnosis.

Upper airway issues, including narrow nasopharyngeal passages, can be made worse by reflux and by enlarged tonsils and adenoids, all of which are more common in children with DS. If these airway issues cause difficulty in breathing or swallowing, your baby will struggle with feeding until the airway issue is managed properly with help from a feeding team. A feeding team may include a speech pathologist, lactation consultant, and/or an ENT. Assessment of your baby's swallow to rule out dysphagia or aspiration may be necessary. See sidebar on swallow studies in this chapter to learn more about how these conditions are diagnosed.

- **Nasal passages** – In addition to airway issues, babies with Down syndrome may also have narrower nasal passages, which may make it more difficult to breathe while breastfeeding. If this is a problem for your baby, he may have to release the breast to take a breath, interrupting the suck-swallow-breathe pattern needed to coordinate a feeding. Allow your baby to pace himself and stop for breaths as needed. If your baby is frequently congested due to small nasal passages or any other reason, clearing his nasal passages with a bulb syringe or other nasal aspirator before each breastfeeding session may help minimize the effect of congestion on his ability to breastfeed. If he is tiring out too quickly from having to relatch multiple times, a nipple shield may allow him to latch more quickly and sustain a latch for longer, increasing milk transfer.
- **Tonsils and adenoids** – Babies with Down syndrome frequently have large tonsils and/or adenoids, or *adenotonsillar hypertrophy*. It is estimated that in individuals with Down syndrome, there is a 50-100% incidence of *obstructive sleep apnea* (OSA), a disorder that causes pauses in breathing during sleep, and enlarged tonsils and adenoids are one of the leading causes of OSA. Babies with large tonsils and adenoids may have an *open mouth resting posture*, where the tongue may be visible and extended, versus resting on the hard palate with the mouth closed. This is common in babies with DS due to low tone, but can be even more pronounced when the baby has enlarged tonsils. While breastfeeding, your baby must be able to breathe through his nose. If enlarged tonsils or adenoids make this more difficult, it may impact his ability to breastfeed comfortably or successfully until the issue is managed.



- **Jaw** – The structure of your baby’s jaw can impact how effective he is at removing milk from your breasts. For example, babies with Down syndrome may have a small and/or receded jaw, which can impact their latch and ability to open widely enough to attach to and compress the breast. Your baby should be assessed for asymmetry, overbite or underbite, how his gums meet, as well as the position of his *mandible*, or jaw bone. Sometimes a small and receded jaw can also occur in conjunction with a tongue-tie, which may make breastfeeding painful or more challenging for your baby, or a buccal tie, which can make it more difficult for your baby to open his mouth wide enough to latch on to your breast. If your baby has any of these challenges, you can help to ensure a good latch with optimal positioning, such as a modified football hold, an asymmetrical latch-on pattern, or in some situations a tongue-tie release, although this procedure can be controversial.
- **Palate** – Sometimes babies with Down syndrome have what’s referred to as a high, vaulted, or “bubble” palate. This can occur as a result of the tongue not reaching the hard palate to shape it in utero and/or from an open mouth resting posture. Babies who are breastfed may have a decreased likelihood of OSA, and it is thought that the act of breastfeeding may change the shape of the baby’s palate, resulting in a more open airway. A high, arched palate is also sometimes indicative of a tongue-tie.
- **Tongue** – It is often thought that babies with Down syndrome have *macroglossia*, or a large tongue, but most do not have true macroglossia. Due to smaller oral cavities, their tongues simply appear to be larger. It may be useful to have an SLP or IBCLC evaluate the function of your baby’s tongue, as the tongue plays an important role in breastfeeding. Some of the things that will be evaluated are your baby’s ability to reach for the breast with his tongue, elevate his tongue to help compress the breast against the hard palate and draw the breast tissue into the mouth, and the grooving of the tongue from front to back. Your baby’s feeding specialist may place a gloved finger in your baby’s mouth to stimulate his sucking reflex, which helps to assess tongue movement.
- **Lips** – An SLP or IBCLC will also look at the structure of your baby’s lips and how they may impact breastfeeding. Normal resting posture for a baby should be with lips together and mouth closed with the tongue resting on the roof of the mouth. A baby with low muscle tone may have his lips apart and open at rest. If the baby has a lip-tie, he may have difficulty flanging his lips, which is necessary to stabilize the breast in order to form a seal. This may result in spillage of milk during breastfeeding. Issues with the lips may also cause the baby to bite down and stabilize at the breast by using his gums. Some external signs of a lip-tie are a thin, flat upper lip that can be tented in appearance.

## Swallow Studies

If there is a suspicion that your baby is aspirating when feeding, his medical team may order a swallow study. During tests, such as a modified barium swallow (MBS) or fiberoptic endoscopic evaluation of swallowing (FEES), your baby's doctors can evaluate his swallow and rule out aspiration. Read more information about each test below and speak to your baby's medical team about the other pros and cons of these studies to determine which is the best for your baby.

- During a modified barium swallow (also known as a videofluoroscopic swallow study), the baby is given expressed breast milk or formula mixed with barium, while video fluoroscopy (a video x-ray) is performed. This enables the radiologist and speech pathologist performing the study to evaluate the baby's swallow function and to see whether liquids are swallowed properly or if they are being aspirated into the lungs. An MBS assesses swallow function using a bottle, and cannot be performed while breastfeeding. Note, some babies may aspirate with bottle feeds but not with breastfeeding, especially if they are not accustomed to drinking from a bottle.
- If your baby is exclusively breastfed and his medical team recommends a swallow study, consider requesting a fiberoptic endoscopic evaluation of swallowing (FEES) study, which can be done while your baby is nursing. In this study, a tiny, flexible endoscope is inserted into the baby's nose, and the speech pathologist and physician can directly observe, in real time, what happens when the baby swallows. This can be performed while the baby is breastfeeding or taking a bottle. Not all medical centers have this option available.

## Possible complications

When assessing your baby's structural anatomy, his feeding specialist may look for evidence of issues that could complicate breastfeeding. The information below is an overview of possible complications and ideas for how to overcome them. If you believe that your baby is experiencing any of the following, contact his medical provider. Especially in the case of aspiration, you should contact your baby's pediatrician immediately.

- **Aspiration** – “Gurgly” vocalizations, increased congestion, coughing, or choking with feedings, and refusal to eat may be signs of aspiration. *Aspiration* occurs when particles of food or liquid are inhaled into the airway. Issues with feeding and swallowing, often referred to as *oropharyngeal dysphagia*, occur more frequently in babies with DS, especially when there are other medical complications. Aspiration can result in serious health issues such as pneumonia. If you believe that your baby is aspirating, you should discuss this with your pediatrician or feeding specialist immediately. Tests such as a *modified barium swallow* (MBS) or *fiberoptic endoscopic evaluation of swallowing* (FEES) can assess the integrity of your baby’s swallow and rule out aspiration. Possible treatment to prevent aspiration may consist of watching your baby’s feeding cues and taking him off the breast if he seems to be getting overwhelmed with your milk flow or the strength of your letdown (see chapter on feeding your newborn for more information about feeding cues). In more serious cases, your baby may need to have thickened feeding to decrease the risk of aspiration, or he may even require tube feedings. Thickened feeds are usually given through a bottle, but check with your baby’s medical team to see if other options are available.
- **Reflux** – Gastrointestinal issues are common in babies with DS, and some may have reflux or gastroesophageal reflux disease (GERD). *Gastroesophageal reflux* occurs when stomach contents come back up into the esophagus and cause heartburn and discomfort. Symptoms of reflux might include crying and arching the back with feedings, frequent vomiting during and after feeds, and refusal to eat. Reflux can sometimes be managed by breastfeeding in a more upright position, such as the biological nurturing position. Breastfeeding is the optimal way to feed a baby with reflux. The shorter, more frequent feedings, common for breastfed babies, allow for faster and easier digestion, often leading to decreased reflux symptoms. GERD is a more severe and longer-lasting form of reflux and can result in more serious feeding issues such as aspiration, difficulty in weight gain, and refusal to eat. If your baby has GERD, he may require medication.
- **Cleft lip and/or palate** – *Clefts* occur during fetal development if there is incomplete closure of the bones of the palate and upper gum and lip. Research has shown that cleft palates and cleft lips occur more frequently in babies with Down syndrome. If your baby has a cleft lip or cleft palate, it is essential to seek professional help with your breastfeeding relationship. If your baby has a cleft lip only, breastfeeding may be possible with minimal intervention. These interventions can include using different nursing positions to help your baby achieve a better seal, shaping your breast tissue (using the C or U hand shape) to ensure that it fills your baby’s mouth, and using the dancer hold to support your baby’s cheeks and jaw. The type and size of the cleft will determine if these positions will be helpful for your baby. If these minimal interventions do not allow your baby to breastfeed successfully, he may need a nipple shield or a nursing supplementer device until the lip is surgically repaired, which is often done as soon as a baby weighs 10 pounds. If your baby needs surgery for a cleft lip, he may be able to nurse

without any special equipment after he recovers. With a ***cleft palate***, the baby may have a cleft of the hard palate, soft palate, or both. A cleft palate may occur in conjunction with a cleft lip. While breastfeeding with a small cleft may be possible in rare cases, such as a small soft palate cleft, the baby is usually unable to create the negative pressure suction needed to transfer milk and breastfeed successfully. Babies with a soft palate cleft may have ***nasal regurgitation*** where the milk comes out of their nose. Breastfeeding in an upright position with your baby's ears above his mouth is safer and will prevent milk from coming out of his nose and getting into his ears. Frequently, babies with a cleft palate require supplementation, either with breast milk or formula. They may also require a special bottle-feeding system. Unless there are other considerations, you should be able to provide your pumped breast milk to your baby, even if he has a cleft palate. Providing breast milk is extremely important for a baby with a cleft, as breast milk can be given closer to surgery than formula due to its rapid digestibility and absorption. Also, babies with cleft palate are more prone to ear infections, and breast milk can provide immunological protection even if it is being given from the bottle.

- **Tongue-Tie** – The piece of tissue located underneath the tongue is called a ***frenulum***. If this tissue has developed along the underside of the tongue close to the tip, it can cause the tongue to be tight, also referred to as ***ankyloglossia***, being “tongue-tied,” or tethered oral tissues. If your baby has a tongue-tie, he may have trouble extending his tongue to reach for the nipple and draw it into his mouth, and it may restrict his ability to elevate his tongue or move it from side to side. Presence of a tongue-tie may impact your baby's ability to latch well onto the breast and can cause damage to the tips of your nipples. It may also impede your baby's ability to sustain a sucking pattern, causing him to frequently pop on and off the breast. With a classic tongue-tie, you may notice that your baby's tongue looks heart-shaped when he cries or tries to lift his tongue. However, there is another form of tongue-tie, referred to as a posterior tongue-tie, which is not as easily identified and is diagnosed by a qualified medical provider. Tongue-ties can be corrected with a ***tongue-tie release***, a simple surgery performed by a trained healthcare professional. More complicated tethered oral tissues should be evaluated by an otolaryngologist (ENT) or dental surgeon. Professional opinions on the need to treat or release certain types of tongue-tie are varied, and more research is needed. Releasing a tongue-tie may not correct breastfeeding problems. Optimal positioning with the help of an IBCLC, experimenting with different holds of the breast and positioning of the baby can often help a baby with a tongue-tie. Use of the asymmetrical latching pattern described in the “large nipples” section can also help a baby with tethered oral tissues achieve a deeper latch.

Despite any structural variations that your baby may have that impact his ability to establish and maintain a breastfeeding relationship, most can be overcome with early assessment and identification by feeding and medical specialists. The key is receiving a timely diagnosis, and intervention and feeding modifications, if needed.

## Mom Story

### AMANDA & MAISE



We found out our unborn child had Trisomy 21 (Down syndrome) when I was 36 weeks pregnant. In a twist of fate, it was our older daughter's fifth birthday. There were no clear signs leading up to her diagnosis, and it was only because she had more amniotic fluid than usual that her medical team requested a genetic marker test.

Maisie was born at 38.5 weeks gestation and had very few complications at birth. She needed a little bit of oxygen and an x-ray of her belly, but otherwise, she was healthy. I had breastfed her sister for 10 months, and I had every intention of breastfeeding Maisie, too. Unfortunately, during the two weeks before her birth, when I was trying to wrap my brain around having a child born with Down syndrome, I was told that breastfeeding likely

would not happen. Sadly, one of my first emotions was that I had no interest in breastfeeding this child—this wasn't the child I wanted or had planned on for 36 weeks! It wasn't until she was born, unearthly warm, purple, and lying on my chest that I decided I needed to breastfeed her, just as I had with her sister, and that I would give her that option, come hell or high water.

During her first exam, everyone noted how strong her suck reflex was. Doctors, nurses, and students all put their fingers in her mouth. They were encouraged; I was encouraged. But every time I brought her to the breast, she didn't know what to do with this squishy thing in her mouth. "Where is that hard thing I've been sucking on?" she seemed to say. I was having problems with letdown and was starting to get anxious. Every cell in my body said, "SHE MUST EAT!" It is a terrible combination of feelings. The doctor said, "She'll be fine. Babies can go a day or two without eating after they are born." But every fiber of my being told me otherwise.

I was five years older, and at 35 years old, my body wasn't remembering its job quite as well as it did when I was 30. To encourage my milk letdown, I started pumping that first evening. I sat in the dark, demanded quiet, concentrated, and willed the milk to pour from me. I kicked everyone out of the room and barked at anyone coming in. All kinds of mental imagery came to me, trying to get my body to wake up: waterfalls pouring from my breast, bright light, rainbows, love. Over and over, I brought the images to my chest. Breathing deeply, I tried to shed that anxiety that was just waiting to take me over. Very slowly, my milk started to come in.

After I had pumped, I tried to bring Maisie back to the breast, but again, she had no interest. I felt defeated. The lactation consultant brought a syringe and a long tube, and we started finger feeding her. She would latch onto a finger and nurse like a champion, so why wouldn't she take my breast?!

*AMANDA & MAISE (CONTINUED)*

Another day, more exams. More amazement at her strong suck reflex. We discussed her need to eat and the need to get her onto a bottle. Then it hit me, why would she want the breast? From the time she was born, people had been sticking their fingers in her mouth. Now she was being fed from a hard finger. It was a light bulb moment! ENOUGH! No more fingers in the mouth! I let it be known, "Look, I know it's unusual for a child with Down syndrome, but I need her to breastfeed!" I didn't see any reason why she couldn't; she had the ability to suck. From then on, it became the breast or bust!

It was the evening of the second day. I had been using a nursing supplementer on my breast with my finger so that when she tried to latch, someone sitting behind me could push some breast milk through the tubing, and my finger would offer that firm support she was most familiar with. It was an immediate reward for trying to suck on the nipple. Then I took the finger away and plumped up my nipple as best I could. I kept the tubing so that she was still getting the milk reward, but now had just the breast instead of the finger.

Late on the evening of the second day, she latched for the first time. I gasped from the surprise that it had finally happened, and from how uncomfortable it was! All I could say was, "She's doing it!" and then I returned to visualizing waterfalls, milk flows, and pouring my soul from my breast into my child. I wasn't going to let this first latch end without giving her every reason to try again.

After that first latch, she needed very little encouragement. I found I had to pump for a few minutes before feeding her to get my milk flow going. While she had a great suck reflex, she lacked the muscle tone and energy to get my milk going. If she wasn't rewarded with milk within a few minutes of trying, she would just give up. By pumping until I had a good flow, I kept her from being too tired to nurse and allowed her to get right down to feeding. She refused all other means of feeding; it truly had turned into "The Breast or Bust!" Over the next few weeks, my milk supply increased significantly. The challenge changed from getting the milk to flow, to preventing it from drowning her. My letdown had such force that it would spray, and because of her low tone, she could neither keep up with the flow nor keep herself from choking. I didn't have much experience with different breastfeeding positions, so I just kept using the same position, sitting upright with her cradled at my breast and dealing with a choking, gasping infant. Because of her tracheomalacia and laryngomalacia (that we did not know about yet), she could not suck AND keep the milk going in the correct direction. So as she nursed, she would choke, gasp, and cry.

At some point, someone suggested trying different positions, and I went to the internet for help. I found many other mothers complaining about their overwhelming milk letdown, and reporting that lying on a bed or couch with their baby facing them at the breast made the letdown much more manageable for the baby. I found the side-lying position, and it became our go-to way to nurse. My letdown was not so aggressive this way, and it didn't overwhelm her. It was such a delightful position, too. I could wrap myself around Maisie and caress her with my free hand. Unfortunately though, nursing while out in public was very challenging. I mostly resorted to going to the car and reclining the seat back to control my letdown.

Maisie breastfed exclusively until at 15 months old, she started to transition to food. For any mother with a child who has Down syndrome, my suggestion for you is to PERSIST. Make your voice heard. If something doesn't work, try something different. Never let someone tell you that your child can't do something just because of an extra chromosome.

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## Medical Complications

EMILY JEAN DAVIDSON, MD, MPH

### **An Overview of Medical Issues that can Impact Breastfeeding**

Compared with the general population, babies who have Down syndrome (DS) have a higher chance of a number of medical conditions such as hypotonia, congenital heart disease, and oropharyngeal dysphagia that can affect their ability to breastfeed. Some of these conditions occur commonly, while others are more unusual. This chapter is intended as a brief overview for you to reference, should your baby be diagnosed with any of these issues. Knowing about these conditions and how they may affect your breastfeeding relationship will allow you to be prepared and to have a plan in place. If you are reading this before your baby is born, realize that the majority of babies with DS can breastfeed from birth despite these potential challenges. Also, with the exception of transient myeloproliferative disorder, which essentially only affects infants with DS, any of the medical issues discussed here can also occur in babies who do not have Down syndrome.



## HYPOTONIA

Hypotonia, or low muscle tone, is found in nearly all babies with Down syndrome. When you hold a baby with DS, her muscles may feel looser or floppier than those of other babies. This low muscle tone affects motor development, including gross motor skills like head and trunk control, sitting, standing, and walking. Lack of head and trunk control may affect the way you need to hold your baby while nursing. Hypotonia can also affect the muscles of the mouth and might make it difficult for your baby to coordinate sucking, moving her tongue, and closing her lips. This difficulty with coordination may mean that your baby takes longer to eat and may drool while eating (see chapter on low muscle tone for a full discussion of hypotonia).

## OROPHARYNGEAL DYSPHAGIA

Poor coordination of the muscles of the *oropharynx*, or mouth and throat, can result in *dysphagia*, or feeding difficulty, which may lead to food and liquid going into the airway, also known as *aspiration*. Babies with *oropharyngeal dysphagia* may cough or gag, or become pale or flushed while eating. They may also sound “junky” or “rattly” after eating. To assess for oropharyngeal dysphagia, a feeding specialist, typically a speech pathologist or occupational therapist, will observe your baby while she is feeding. If further information is needed, additional studies can be performed to see if fluids are being swallowed correctly. In a *modified barium swallow* (MBS, also known as a videofluoroscopic swallow study), the baby is bottle fed expressed breast milk or formula mixed with barium, while videofluoroscopy (a video x-ray) is performed. This enables the radiologist and speech pathologist performing the study to evaluate her swallow function and to see whether liquids are swallowed properly or whether there is aspiration of the liquids into her lungs. Another option available at some centers is a *fiberoptic endoscopic evaluation of swallowing* (FEES). In this study, a tiny flexible endoscope is inserted into the baby’s nose, and the speech pathologist and physician can directly observe, in real time, what happens when the baby swallows. This can be performed while the baby is breastfeeding or taking a bottle.

## HEART AND RELATED CONDITIONS

Around half of all babies with Down syndrome are born with heart defects. In comparison, about one percent of babies in the general population are born with heart defects (see chapter on heart conditions for more information). The most common cardiac defects in babies with DS include:

- **Atrioventricular canal defects** (also known as **common atrioventricular canal** or **CAVC**) occur most frequently. These defects can be located in the *septum*, or muscular wall that separates the left and right sides of the heart, or in the valves between the chambers of the heart.
- **Ventricular septal defect** (or **VSD**) is a defect of the wall between the pumping chambers.
- **Atrial septal defects** (or **ASD**) is a defect of the filling chambers.
- Other defects are less common (though still more common than in the general population). These include:
  - **Partial atrioventricular canal defects**
  - **Patent ductus arteriosus**: the persistence of a prenatal connection between the pulmonary artery and the aorta, which normally closes after birth
  - **Tetralogy of Fallot**: a combination of a narrowing of the pulmonary artery, a ventricular septal defect, an overriding aortic arch that goes over both ventricles instead of just the left, and right ventricular *hypertrophy* or thickening of the wall of the right ventricle

Some of these defects will get smaller and then resolve on their own without any treatment, and some will require surgical repair, or can be repaired via a *cardiac catheterization procedure*, in which the doctor uses a small catheter inserted through a large vein in the baby's leg and then threaded to the heart. Fortunately, most babies with DS who have heart defects do not have significant symptoms at birth. They can typically go home and be monitored as an outpatient until it is determined whether surgery is needed.

A baby who has a heart defect might have some of the following symptoms: *cyanosis*, or a purplish color of the skin\*, shortness of breath, rapid breathing, or difficulty feeding due to breathing difficulties or tiredness. If your baby has any of these symptoms please contact her doctor right away. Symptoms requiring emergency response (911) include difficulty breathing or new *central cyanosis*, or a blue or purple color to the lips and mouth. Some babies with complex congenital heart disease have central cyanosis at baseline; in that case, your baby's cardiologist will let you know what symptoms require emergency care.

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\*Note that parents of many newborns and of many older kids with Down syndrome may notice that their children's hands or feet appear a little purple, especially when they are cold. (This can occur even if a child does not have Down syndrome). If this purple or blue color appears only in the hands or feet, known as *peripheral cyanosis*, but not in the lips and mouth, also known as central cyanosis, it is most likely not a concern. However, do discuss this with your child's pediatrician or cardiologist.

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***Pulmonary hypertension***, an elevated pressure in the pulmonary vessels and right side of the heart, is found in 1-5% of babies with DS (more often than in the general population). This condition can occur in babies with and without congenital cardiac defects, may be treated with oxygen or medications, and requires follow up with a cardiologist. Pulmonary hypertension alone is not likely to affect breastfeeding, but medications used to treat it can sometimes cause nausea or vomiting.

If a cardiac condition is affecting feeding (for example, if your baby gets tired or short of breath when eating), her medical team may recommend using a nasogastric (NG) tube. If so, your baby may still be able to have shorter trials of breastfeeding, and you can pump and store milk to be given via the NG tube.

## MALFORMATIONS OF THE GASTROINTESTINAL TRACT

About five percent of babies with Down syndrome are born with a defect in the ***gastrointestinal*** (GI) tract. The most common of those are duodenal stenosis/duodenal atresia. Some of these abnormalities of the GI tract require surgery in the newborn period, and the recovery time can delay the start of breastfeeding. While your baby is recovering, she will likely be fed through a feeding tube, which will be used to carry food directly to her stomach or intestines. If your baby is having surgery immediately after birth, or is unable to use her GI tract, it is important that you start pumping your breast milk soon after delivery. The nursing and lactation staff will assist you in how and when to pump. It is also recommended that you hand express your ***colostrum*** (early milk), as this can increase the overall volume of milk you make for your baby. Your healthcare team will teach you more about this, if needed, but if you are unable to attempt to directly nurse your baby, it will be helpful to ask about pumping as soon after delivery as possible. In most cases, your expressed breast milk can be fed through your baby's feeding tube.

### Duodenal atresia or stenosis

***Duodenal atresia*** is a complete blockage of the ***duodenum***, the part of the small intestine closest to the stomach. ***Duodenal stenosis*** is a narrowing of the duodenum. With this condition, food is either partially or completely blocked from passing from the stomach through the small intestine, resulting in vomiting and inability to take in nutrition. If the blockage is complete, there may be signs on the prenatal ultrasound. If the blockage is not identified until after birth, the baby might try to feed but would soon begin vomiting as her stomach cannot empty into her intestines. An upper GI study (MBS), in which the baby takes barium mixed with breast milk or formula, can show the abnormality. This condition is treated by surgery, typically within the first few days of life. Until the surgery, a tube is placed from the nose or mouth to the stomach to allow the stomach secretions to drain, and the baby is given nutrition through an intravenous (IV) line.

## Esophageal atresia

In this condition, the *esophagus*, which is supposed to lead from the mouth to the stomach, ends in a closed pouch instead, so food is completely blocked from going into the stomach and intestines. This requires surgical repair. If the distance, or gap, between the closed pouch at the top of the esophagus and the bottom of the esophagus is small, the two ends can be surgically connected directly. That surgery would be performed within the first few days of life. If the distance between the two parts of the esophagus is too large to connect directly (also known as *long gap esophageal atresia*), a different solution is needed. At some hospitals, a procedure called the Foker Process can be done to place the two ends of the esophagus under traction and gradually allow them to grow closer together until they can be connected directly. This typically requires a long hospital stay (months) but can have better long-term results than other approaches. Until the esophagus can be reconnected, typically a gastrostomy (G-tube) is placed to feed the baby. If your baby has long gap esophageal atresia, you can pump your milk and give it to her by G-tube.

## Tracheoesophageal fistula

This is an abnormal connection between the airway and the esophagus, which can allow food to be aspirated into the lungs. This condition requires surgical repair, typically within the first few days of life. Intravenous nutrition is given until the repair can be made. A baby may have a tracheoesophageal fistula in combination with esophageal atresia.

## Imperforate anus

In this condition, there is a blockage in the opening at the anus. It may be diagnosed immediately after birth during your baby's first physical exam, or in the first few days if the external anus appears normal but the baby does not pass *meconium* (the first bowel movement) within the first 24 to 48 hours of life. If the blockage is partial, it might be improved through dilation procedures. If dilation procedures are not successful or if there is complete blockage of the anus, then surgery will be required.

## Hirschsprung's disease

Children with *Hirschsprung's disease* have abnormal nerves in part or all of the colon. This leads to significant constipation and/or bloating because the affected areas cannot produce *peristalsis*, the normal movements that are required for the child to pass a stool. Hirschsprung's is treated by surgically removing the affected part of the colon. Some children with Hirschsprung's are diagnosed if they do not pass meconium within 24 to 48 hours of life, but sometimes the diagnosis does not occur until early childhood when the child is noted to have significant constipation.

A radiologic study in which a contrast such as barium is put into the rectum can show the area of abnormality. Sometimes *manometry* (a test of the function of the muscles in the colon) can provide information that is helpful in making the diagnosis. A definitive diagnosis can be made by taking a biopsy of the affected area to see if the nerve cells are present. If the area of abnormality is small, the affected area can be surgically removed and the bowel reconnected (sometimes called a *pull-through*). If the area is larger, there may not be enough colon left to reattach after the affected area has been removed. In that case, an *ostomy* (hole) is made to allow the stool to come out of the body and into a collection bag that is in place on the lower abdomen. Many babies with Hirschsprung's can breastfeed from the start; however, symptoms associated with Hirschsprung's prior to treatment (for example, constipation, gassiness, or reflux) might impact your baby's ability to breastfeed prior to surgery.

## TRANSIENT MYELOPROLIFERATIVE DISORDER (TMD)

Also known as *transient abnormal myelopoiesis* or *transient leukemia*, TMD is an abnormality that occurs almost exclusively in babies with Down syndrome. It is present in 10–30% of babies with Down syndrome at birth. With this condition, there is an abnormal number of immature blood cells or *blasts* in the bloodstream. Typically, this disorder is short-lived, or *transient*, and will go away within a few months without treatment, but for some babies with TMD, the condition can evolve into a form of leukemia called *acute myeloproliferative leukemia*.

TMD is diagnosed through a blood test at birth (though sometimes in severe cases, there may be indications on the prenatal ultrasound). If TMD is found, a doctor who specializes in blood disorders, known as a *hematologist*, will monitor your child closely with follow-up blood tests every three months until age 4. In most cases, TMD will not interfere with breastfeeding. In about 20% of babies with TMD, there are more significant medical complications, including liver dysfunction, fluid around the heart, very high white blood cell count, bleeding problems, or *hydrops fetalis*. Hydrops fetalis refers to an abnormal collection of fluid in at least two areas, including the abdomen (*ascites*), around the lungs (*pleural effusion*), around the heart (*pericardial effusion*), or of the skin and soft tissues (*edema*). Babies in this high-risk group may not be able to eat by mouth initially, while their underlying issues are treated. In that case, pumping to establish a supply and providing your baby with your expressed milk via tube feedings can help ensure that you have milk available when your baby is ready to try direct breastfeeding after recovery.

## Support Services in the Hospital • HEATHER MILLER

Finding time for yourself during your child's hospitalizations can be difficult, but it is critical to keeping your sanity. This is especially true if you are providing your baby nutrition through breastfeeding or expressing milk for later use. To help you during this stressful time, see if your hospital offers any of the following:

### **Breastfeeding support**

Many hospitals provide additional services to breastfeeding mothers, including:

- Free meals delivered to your child's room from the hospital kitchen
- Access to a lactation consultant
- Access to a hospital-grade breast pump for use while at the hospital
- A secure place to store expressed breast milk

### **Respite services**

Many children's hospitals have a service that arranges for a volunteer to visit with your child so you can spend some time away from the hospital room. You may only need 15 minutes to take a walk and buy a real coffee, an hour to go for a run, or a few hours to catch up with family or friends over a meal. This allows you time to have a break and gives your child the opportunity to be with someone who is not a medical professional but is there simply to provide a comforting presence and engage in ordinary kid stuff. We know that it may be difficult for you to leave your child, but it is important to find time to care for yourself.

### **Child life services**

Child life specialists are members of your child's healthcare team who focus on supporting child development during hospitalization. They may bring developmentally appropriate toys or games to the bedside, or musical and art activities for older children, and can provide you with professional assistance to help siblings cope with the hospitalization of a family member. Music therapy may also be available.

### **Wellness services**

Many hospitals offer programs for family members such as Reiki, massage, chair yoga, coffee hour, or even free passes to local gyms for a workout. Ask if the hospital has a family resource center where you can learn more about programs that may be available.

### **Social services**

Request to meet with a social worker or resource specialist. They have a wealth of knowledge about services available in the hospital, financial resources, parking assistance, and more. They can also be someone to talk to about the emotional toll a hospital stay may be having on you and your family. A social worker can also help you learn how to participate as a member of your baby's healthcare team and advocate for your child.

### **Family sleep space**

If you are staying with your child in the Neonatal Intensive Care Unit or Pediatric Intensive Care Unit, ask if there are any special sleep spaces available for you to have a quiet, private spot to get some rest. Many hospitals also offer breastfeeding mothers the option to room in with their babies.

### **Kitchen**

Many pediatric floors have kitchens with freezers, fridges, and microwaves for parents to store and heat up food from home.

### **Water**

Most hospitals have drinking fountains or water dispensers available, and some may even offer flavor-infused water.

## HYPOTHYROIDISM

Babies with Down syndrome have an increased risk of *hypothyroidism*, or insufficient thyroid hormone. Hypothyroidism is detected by a blood test soon after birth, and screening may be included with the *newborn screen* (the heel prick that all babies get after birth to screen for treatable metabolic and genetic conditions). The universal newborn screen in your state may include thyroid hormone or thyroid-stimulating hormone (TSH) or both. For babies with Down syndrome, the screen should include both of these tests, which can be added to the state screen if your state only routinely sends one or the other. In cases of severe hypothyroidism, the baby may be very sleepy and not feed well. Even for babies who are not symptomatic, thyroid hormone is necessary for normal growth and brain development. If your baby is found to have hypothyroidism, it is important to treat her with daily thyroid hormone replacement under the guidance of an endocrinologist.

## PREMATURITY

Babies with Down syndrome are more likely to be born *prematurely*, or before their due date, compared to the general population. Premature babies often have more difficulty with breathing (due to lung immaturity) and may require the support of a ventilator initially. They are also more vulnerable to infection, can have difficulty with *hyperbilirubinemia* also known as jaundice (due to immaturity of the liver), and are at higher risk for *intraventricular hemorrhage* (bleeding in the brain). If your baby is born prematurely (particularly before 34 weeks), it may be helpful to learn more about the potential issues for babies born prematurely and recommendations for their care. There are several books for families on this topic.

Often, babies who are born early do not have a fully developed suck and swallow coordination, and have challenges feeding directly at the breast. If this is the case for your baby, you may be able to use other options for giving expressed breast milk to your baby. If these techniques do not work well for your baby, or your baby is too premature or too sick to eat by mouth, a nasogastric (NG) tube can be placed to give her your milk while she continues to grow and mature. If you are separated from your baby because she needs to be in a Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN), your healthcare team will recommend that you start pumping milk for your newborn as soon as possible. Although most NICUs are not set up with parent sleeping arrangements right next to the baby, parents are nearly always welcome at the baby's bedside (except sometimes during a medical procedure or an emergency). Discuss with your baby's medical provider how to optimize the amount of time you can spend with your baby. Also, make sure to take care of your own recovery. It is important to get enough rest, and you may ultimately be able to do more for your child if you can go home or go to a parent sleep space to get some good sleep.

## ILLNESS

Babies with Down syndrome can, of course, have the same types of medical illnesses that other babies may have in the newborn period such as hyperbilirubinemia, respiratory issues, and infections. Many of these illnesses occur at higher rates in children with Down syndrome than in the general population. Any significant medical illness can temporarily affect a baby's ability to nurse or to take anything by mouth. As long as your baby's medical team lets you know it is safe for your baby to eat, you should be able to try breastfeeding.

### MEDICAL ISSUES IN THE NEWBORN WITH DS UNRELATED TO BREASTFEEDING

Babies with Down syndrome have a higher, although still rare, chance of being born with *cataracts* (cloudiness of the lens in the eyes) and a higher risk of hearing issues. Neither of these conditions should affect breastfeeding, but it is important to make sure that a physician or nurse practitioner has looked at your baby's eyes using an ophthalmoscope to ensure that the *red reflex* is present (showing that light can get to the retina without obstruction), and that your baby has a hearing test before discharge.



## Mom Story

### AIMEE & CATHERINE



Catherine was born with duodenal atresia, a blocked common bile duct, and several heart complications including a complete AV canal defect with tetralogy of Fallot, in addition to Down syndrome. She required multiple surgeries soon after birth and spent the first eighty days of her life in the hospital. We knew that Catherine would have Down syndrome early in our pregnancy, and despite all of my worries, I knew that we would be fine if she could breastfeed.

Catherine's first surgery, the repair of her duodenal atresia, happened when she was just four days old. It is a relatively simple surgical repair, but the condition can be life-threatening if the repair is not done soon after birth. While Catherine was healing from her duodenal atresia repair, she had to receive all feedings through a nasogastric (NG) tube. She kept the NG tube in for more than four months.

From the time Catherine was born, I worked with the lactation consultants at the hospital to pump and develop my milk supply. We gave Catherine this milk, fortified with formula to increase the calories, through her NG tube.

Catherine's heart condition required that her heart and lungs work overtime, so she didn't have any reserve energy left over to nurse. Her low tone caused her to have a weak suck and put her at risk for aspirating. Despite all the health challenges, I was determined to breastfeed her. Having a newborn in such a medicalized environment seemed incredibly abnormal to me, and I felt that nursing Catherine, as I had her older brother, would make things seem a bit more normal. With the encouragement of lactation consultants, I continued trying to get Catherine to latch properly, working with her frequently with the ultimate goal of having her directly nurse at the breast. After her heart repair, Catherine gradually began to have longer periods of wakefulness, and her suck became stronger and more coordinated.

Once we were home, at about four months old, Catherine pulled out her NG tube, and I thought *this is it; we have to make this work*. I felt like Catherine needed to take this opportunity to figure out how to directly nurse at the breast because I knew I couldn't keep pumping for much longer. I had read that children who have a history of an NG tube from birth sometimes have oral aversions and have a difficult time taking anything by mouth. However, I put Catherine to breast and she nursed like she had been doing it for her whole life. It was like all the stars aligned for her...and for me...I felt...*we can really do this*.

Despite significant medical challenges, several surgeries, and weeks in the hospital, we persevered. My desire to have Catherine nurse at the breast was always in the forefront of my mind. Even though pumping can be difficult, I feel that the reward was worth it.

## Mom Story

### SHANNON & ROBIN



I gave birth to Robin, a little girl with Down syndrome, in April. She was diagnosed at birth (even though there had been no evidence during prenatal testing), and we spent the better part of a month in the NICU with most of the common issues one could expect: slow heart rate, poor respiratory function, low weight, and poor intake. I was told, “This isn’t a mom problem; it’s a medical problem. You should go home and rest.” But I am a nurse, so, although I knew so little about DS at that point, I figured that breastfeeding might be one of the best ways to improve the poor muscle tone that we learned was contributing to her health issues. I stayed at her bassinet every single day and night, opting to try nursing at every opportunity. I was often in tears as the care staff blamed Robin’s drop in oxygen saturation and heart rate on me “tiring her out again.” Robin is a fighter, just like me, and though she struggled greatly, we did get her latched with the aid of a nipple shield. She was discharged from our NICU as the only baby on the ward who was exclusively breastfed!

We had a long road ahead of us, as she required weighing before and after each feed for several months. But Robin eventually got the hang of breastfeeding without the nipple shield and has been exclusively breastfed without any devices since then.

As mothers, we all have the desire to do the absolute best we can for our children, whether they are genetically typical or not. Breastfeeding is a gift that we are given. It’s not reserved for typical kids. It’s the first step to protecting and loving these precious little babies. At a time when I was desperately hopeless and lost, unsure of how to raise a child with special needs, or how to prepare my five-year-old daughter for what life was about to toss our way, it occurred to me that Robin was just a little girl who didn’t ask for her life to be any harder than her sister’s. As her mom, my job was to be everything Robin needed, when she needed it, just the same as I was with her sister. Robin has already enriched our lives with so much gratitude and pride. Our bond began over the struggle and perseverance it took to breastfeed, but breastfeeding was only our first goal. Now we are onward and upward!

## Mom Story

### SARA DAWN & ADEMAR



Our son, Ademar, was diagnosed with Down syndrome the morning after he was born. We had a beautiful planned home birth with the support of a licensed midwife who helped him latch within an hour of his arrival. He had no problems with nursing, and we breastfed successfully for four days until he was admitted to our local hospital for Rh incompatibility jaundice.

This hospitalization disrupted the evolution of our breastfeeding relationship since he had to lie under the UV lights to bring his bilirubin levels down. The medical staff started an IV for hydration, and he had layers of monitors and cords taped to his body that made it difficult to hold and feed him.

Ademar was often too sleepy to suck efficiently, so we were taught to finger feed him. Later, we used a supplemental nurser, and his nurses started weighing him before and after breastfeeding sessions to measure his milk intake. At that point, I breastfed him first, and then, when he became too tired to nurse, I would finger feed him expressed milk. He was able to latch and nurse during our stay.

His weight dropped over the next few days as the excess fluids from the IV left his body. We immediately began waking him at night for extra feeds. He was too sleepy to latch on during these middle-of-the-night feeding sessions, so we used the finger feeding method. Over the next week, he began to breastfeed less and less. I would bring him to the breast, and he would purse his lips as if trying to suck on a straw or a finger! Add to that his nighttime sleepiness, and our situation began to feel hopeless. Ademar would nurse only one or two times per day and would bottle feed the rest. We saw several lactation consultants, but he latched on and nursed perfectly during our appointments, so the lactation consultant was never able to observe his feeding problems!

*SARA DAWN & ADEMAR (CONTINUED)*

Breastfeeding Ademar has been by far one of the most emotionally challenging times of my life. I knew about the many nutritional benefits of breast milk, the improvement of muscle tone through nursing, and the emotional bond and behavioral benefits of full-term breastfeeding. I did not want to lose it all so soon, even if Ademar could still have my milk through a bottle. I desperately wanted him to nurse at the breast. I was devastated and feeling quite lost, but then my midwife reminded me of our first four days of successful nursing and his perfect latch. She believed in me. She believed in him. She saw how well we were doing in the beginning, and she encouraged us to keep trying. Because of her, I was able to keep going.

I asked our IBCLCs how to get a better latch, but nothing really helped. Between late-night feedings, I began Googling and searching through books to find tips to get my son to open his mouth wider when I brought him to the breast.

The first tip I found was to hold my breast with thumb on top and index finger supporting beneath, and to catch his chin and gently pull it open wider as he began to latch on. The next tip I found was to flip my nipple into his mouth to get a deeper latch by first lifting it over his upper lip and then tucking it up into his mouth as he latched on. I found videos on YouTube showing how to do this, which was great because I am a visual learner! Over the next several weeks, we progressed and were able to replace most bottle feedings with breastfeeding, and he was still gaining weight wonderfully.

Around 10 weeks his growth slowed down. I continued pumping and supplement feeding with the SNS and additional bottle-feeds when he was too sleepy to nurse. We found a new IBCLC who helped me overcome my mounting anxiety and stress about breastfeeding and find the joy of it again. She helped us with our latch by reminding me to bring him in closer to the breast so that both his chin and nose were touching it. She helped me find exercises and resources for oral therapy and for working with low muscle tone. She answered all my questions about pumping, bottle feeding, using the SNS, and various breastfeeding techniques and positions. I felt so supported as she went out of her way time and time again to find us resources in our rural area. She made breastfeeding fun for us again, which is something we had lost along the way.

Despite all our efforts, my son had only gained three ounces during the prior two months. I happened to mention to our IBCLC that he had slimy poops, and she felt strongly that could be due to a food sensitivity. Knowing that a higher percentage of people with DS also have celiac disease, I decided to stop eating all forms of gluten. Within one week, my son gained one pound. I next stopped eating all dairy, and the following week he gained almost two pounds!

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Rachel and Anna

## Low Muscle Tone

JENNY THOMAS, MD, MPH, IBCLC

Approximately 90% of children with Down syndrome (DS) have low muscle tone, also called *hypotonia*. Low tone can make breastfeeding your baby challenging, but most babies with DS can successfully feed at the breast, and we should give them every chance to do so. Additionally, there is no evidence that a baby with DS feeds better with a bottle or needs to trial feeding with a bottle, especially in the absence of other medical challenges. Many mothers of children who had early problems nursing report that their baby was breastfeeding successfully by 3-4 months of age.

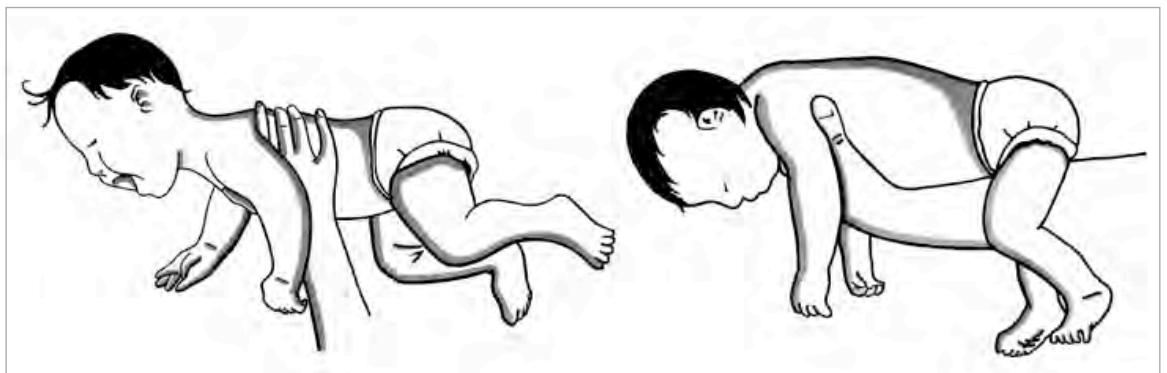
## UNDERSTANDING MUSCLE TONE

To understand how your baby with Down syndrome differs in muscle function from other children, we need to understand how muscles typically function. It may be helpful to review some definitions:

- **Bulk** or **mass** is the physical size of the muscle.
- **Strength** refers to the amount of force a muscle can produce with a single maximal effort and is usually measured while the muscle is in a state of contraction.
- **Tone** describes how well the muscle can resist the pull of gravity.
- **Endurance** is the ability of the muscle to work at a steady performance rate over time.

No muscle stays completely relaxed, and as long as a person is conscious, his muscles remain slightly contracted. Tone keeps bones in place and allows a person to remain standing, to sit up straight, or to maintain any other position. In a person who has low tone, the muscles do not fully contract before they relax again. Problems with tone can happen with or without problems with strength. Overcoming low tone requires effort and energy, leading a baby with hypotonia to tire more easily during everyday activities such as nursing or playing.

Breastfeeding can be challenging for babies with low tone because they often have abnormal or underdeveloped control of the structures in the mouth and *pharynx*, or throat, which can lead to a weaker suck, making it difficult for them to extract milk from a breast or bottle.



*This is how a baby's tone is determined: The child on the left can elevate his head and keep his back straight with minimal help from the examiner. The child on the right cannot lift his head against the pull of gravity and the examiner is nearly completely supporting him.*

*Illustration by Jason Branson ([www.JasonBranson.com](http://www.JasonBranson.com)) © 2018 Jenny Thomas, MD, MPH, IBCL*



## Pro Tip

Just because a baby with Down syndrome is not breastfeeding by the time he leaves the hospital does not mean that he never will. As with many other things, babies with DS sometimes take a little longer to get it. Because of this delay, your support and encouragement are critical. If we know that it may take a few months for a baby with DS to get better at breastfeeding, we can support the process in the following ways:

- While still in the hospital, refer your patient to a lactation consultant and a speech therapist who specializes in feeding issues. Inform them of the mother's decision to breastfeed and work with them to come up with a team approach to help her achieve this goal.
- Encourage the mother to begin expressing her breast milk right away to ensure that her supply will be adequate when her baby is ready to nurse (see pumping chapter for more detailed information about how a mother can initiate her milk supply when her baby is unable to suckle).
- Before discharge, make a referral for Early Intervention services for the baby, if they are available in your area.
- Give the family information about local DS organizations that may be able to help connect the mother with other mothers who have breastfed their babies with Down syndrome. See resources in the appendix for more information.
- Provide your patient with web-based or print resources. See appendix for a comprehensive list.
- Develop a comprehensive *going home plan* to help the baby get to the breast. This plan should include a referral to an outpatient lactation consultant, a speech therapist who works with feeding issues, and a recommendation to obtain a hospital-grade pump, if at all possible, to allow the mother to maintain her milk supply while her baby is learning to feed.

## WHAT POSITIONS WILL HELP ME BREASTFEED MOST SUCCESSFULLY?

While your baby is nursing at the breast, you may need to provide extra support for his body and head to counteract his low tone. If you are sitting in a chair to feed your baby, use pillows in your lap and under your arms to bring your baby up to the level of the breast. This will ensure proper support for your baby, while also helping to keep your body comfortable during feeding sessions. For additional support for yourself, consider raising your feet slightly on a footstool, which encourages you to sit back in your chair, supporting your lower back, and preventing your body from fatiguing as quickly. As you and your baby get better at breastfeeding, you may not need to use pillows and positioning aids. The traditional breastfeeding position of mom sitting upright, cradling a baby in her arms, may not be the best position for you and your child, at least not when your baby is a newborn. However, the laid-back and dancer hand positions may be more helpful than others.





## Dancer hand position

If your baby has a loose seal around your nipple, he may not suckle well enough to remove milk, or your milk may leak out. The dancer hand position supports your baby's chin and cheeks, which can help compensate for the low tone in his cheeks and jaw, allowing him to transfer more milk. Supporting your baby's jaw in this way also reduces the amount of pressure from the breast on his chin.

To use the dancer hand position, cup your baby's chin using the hand that is on the opposite side that your baby will nurse from. Place your index finger on one side of his jaw and your thumb on the other side of your baby's cheeks, which makes the space inside the mouth smaller, and increases the pressure the baby applies to the breast. Your other three fingers will be underneath your breast to help lift it up and guide it toward your baby. Gentle upward pressure under the chin, behind the jawbone, can help support the movement of the tongue. Take care to keep your hands on your baby's face and not near his throat, as that will be uncomfortable for him. You can use your free hand or a pillow to support your baby in this position. He can either be positioned upright or across your body.

## Reclined or laid-back position

A reclined or laid-back nursing position can be helpful if your baby is overwhelmed by the fast flow of your milk letdown. It can also be helpful for women with larger breasts. This position is thought to activate a baby's natural feeding instincts, and may provide more stability for your baby. Use a reclining chair or bed that will let your body tilt backward, ideally at 45 degrees, with your head and shoulders well supported and your baby belly-to-belly with you. Put your baby on his belly with his head at the level of your breast. You don't need pillows for your baby since your body will provide any additional support he may need. Gravity helps your baby rest his chin on

your breast to get a deeper latch. Since your hands are free, you can use them to guide your baby into the right position. He can lie across your body, parallel with your body, or in whatever position is most comfortable to you both.

### Mom Tip

You may worry that there is a short window of time during which your baby must learn to breastfeed, or he will never get it. However, research on children with DS and many stories from other parents have shown that this is not necessarily true.

If needed, stroke the bottoms of your baby's feet; this stimulation helps to wake up his tongue and mouth reflexes for feeding. If your breast is very large or heavy, the weight may be too much for your baby to hold against his face and jaw. You can help your baby by holding and supporting your breast throughout the feeding. You can also put a small rolled towel under your breast to help lift the weight off your baby. Try not to grab the back of your baby's head and push it towards your breast, as this may cause your baby to push away by reflex. Instead, apply a gentle, steady pressure at the base of your baby's head and upper back/shoulders toward the breast to support suckling.



*Reclined or Laid-back position*  
Illustration ©2019 Julia Eva Bacon

Your baby's low tone may present some challenges when attempting to breastfeed, but by understanding these challenges and using the tips outlined in this chapter, it is highly likely that you will be able to overcome them and have a successful breastfeeding relationship with your baby.

## Mom Story

### ALICE & TEDDY



Teddy was breech, so his birth was a planned cesarean section. My husband and I watched Teddy arrive somewhat inelegantly into the world due to being wrenched out bottom first! He cried, turned a lovely color, was quickly checked, and then he was put on my chest for skin-to-skin contact. He scooted around my chest and tried to latch. We looked into each other's eyes, and I said, "Hi baby, it's so amazing to meet you!"

After Teddy was weighed, and I was checked over, I was able to feed him. He nursed for ages and knew just what to do! I noticed that his face seemed a bit flat, but was reassured that this was because he had been breech and that his head shape would change later.

Teddy did great during his checkup the next morning, and no issues were raised. The doctor asked if Teddy looked like anyone in the family, and I confirmed that his nose and lips were similar to his brother's. For some reason, this didn't sit comfortably with me, and I kept asking my husband what the doctor meant with that question. We went home that afternoon to start our life as a family of four.

By day three, when the midwives visited us, Teddy had gained 40 grams! He was breastfed on demand and was doing brilliantly. But problems started soon enough. He was weighed every few days, and even though he always gained some weight, it was not sufficient. I became concerned as my first son gained weight very quickly, and I knew it wasn't a milk production issue. At two weeks old, Teddy became jaundiced, and we were referred to the hospital.

The doctors at the hospital felt that Teddy was floppy, and agreed that in a month or two, they could do genetic testing. I demanded that the testing be done right away, as I'd had suspicions for some time that all was not well with my Teddy. Blood was drawn, and we went home to anxiously await the results.

*ALICE & TEDDY (CONTINUED)*

The next day we learned that he had polycythemia (elevated hematocrit) and was severely dehydrated, despite no clinical signs when the blood was taken. Teddy was admitted to the hospital that night for failure to thrive, and we were told that Teddy needed top-up feedings, by a bottle initially, but if that failed, he would need an NG tube. They also suggested that I could express my milk, but that if I didn't make enough, he would need formula.

I had breastfed my first baby for over a year, I know about breastfeeding, and I know my boobs! I knew this wasn't a supply issue regardless of what the medical professionals thought. Thankfully, our doctors were supportive of my wish to breastfeed, and one of the nurses went out of her way to encourage me. I started expressing and tried to make enough to give him an extra two ounces every four hours on top of his feeding at the breast. The pump and I set to work, and we made all that he needed and more. He was a trouper and approached bottle feeding like breastfeeding, and latched, sucking until he was finished!

Still, nobody knew what was wrong. The doctors said we needed to wait for the blood work to come back as they felt the answer was in his genetics. We were discharged three days later. I am very proud of the sentence in his report, "Hospitalized due to poor weight gain, despite excellent maternal milk supply!"

We went back the next afternoon to meet with the consultants for the blood tests results, and we were told that Teddy had trisomy of his 21st chromosome, or Down syndrome. For me, this was a relief as there are so many worse health issues. Down syndrome is well mapped, well known, and recognizable. Most health complications can be treated and, compared to many other alternatives, it isn't life-limiting! It's still hard some days as it was such a shock, but it answered the questions I had been asking, and I am eternally grateful for the care and compassion shown by all the medical professionals.

Within a few weeks of being home, we relaxed the feeding/expressing schedule. As long as Teddy had regular breastfeeds of a decent length, and still had a big bottle of expressed milk, he was fine. His weight just went up!

Many people say how hard it is for babies with DS to breastfeed, and for many, it is—but sometimes it isn't. When I compare my own experience to my friends' experiences with their children who don't have Down syndrome, I don't think it's all that much different!

## Mom Story

### IMELDA & TIM



Tim is 33 now and was born with patent ductus arteriosus, which required surgery when he was 17 months old.

He suckled for 40 minutes immediately after he was born, but for a while after that, it was a struggle. I had successfully breastfed my first child, which was a help.

Following his birth, Tim wouldn't suckle again, and after 12 hours, he went into the Special Care Baby Unit. I had a lot of milk, so I expressed it by the bottleful, and it was given to him through his NG tube. After about a week, I went home to my 2-year-old daughter, going back to the hospital daily to express milk.

The nurses persevered, and after two weeks, Tim started to take a bottle and was able to come home. Our midwife met us at home that first day and showed me how to latch him on to the breast.

I held one arm along his back with my hand cradling his head, my other hand holding my breast. It was almost a hooking-on, as I angled his head with his open mouth slightly above my nipple. Then I got as much of the nipple into his mouth as possible with my hand holding the breast. It worked for us, and Tim was fully breastfed from then on. He fed every four hours and refused to touch a bottle ever again.

I had been warned that it was unlikely that I would be able to breastfeed Tim because he had Down syndrome, but I was determined. My previous experience was a great help. Breastfeeding helped me bond with Tim, and I am glad that I didn't listen to those who said he couldn't do it.

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*Julie breastfeeding Logan in the NICU*

## The NICU Experience

JEANETTE ZAICHKIN, RN, MN, NNP-BC

While some infants with Down syndrome are able to stay in a well-baby nursery or room in with their mothers, many are admitted to the Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN). The NICU can be a new and frightening experience for many parents. It takes time to adjust to the routine, learn how to care for your baby, and learn how to communicate with the healthcare team.

If your baby is admitted to the NICU or SCN, you may face additional challenges to meeting your goal of breastfeeding your baby. This chapter offers information and strategies for helping you meet those goals while navigating the NICU and becoming a valuable partner in your child's care.



## WHAT IS THE PLAN FOR SKIN-TO-SKIN CARE AND NICU ADMISSION?

If you learned during your pregnancy that your baby has Down syndrome, your obstetric provider may have already spoken with the NICU care team so that they could work together to develop your baby's plan of care. In most cases, the physician, physician assistant (PA), or neonatal nurse practitioner (NNP) who will attend your baby's birth and care for her will talk with you before the birth to understand your wishes and to review the plan. Skin-to-skin contact immediately after birth is highly encouraged for any mother, but especially for a mother who would like to breastfeed her baby. Skin-to-skin contact means that your new baby is placed with her bare chest touching your bare chest. Research has shown that skin-to-skin contact helps to increase breastfeeding rates and duration.

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The highest priority for the neonatal team in the delivery room is to make sure that your newborn makes a successful transition to life outside the womb. It is difficult for the baby's medical provider to make promises about events at birth, such as immediate skin-to-skin contact, because resuscitation becomes the priority if a baby is not active and breathing. However, if your baby is full term (or nearly full term), doing well (breathing without distress and maintaining a normal heart rate), and has no other conditions that might affect her abilities to continue to do well, the neonatology team will do their best to accommodate your wishes while monitoring her condition.

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Skin-to-skin contact between a mother and her healthy newborn is routine after a vaginal birth, but if you are having a planned cesarean birth (c-section), you can ask about skin-to-skin care before your delivery date. As long as you and your baby are both doing well, many birthing units make the extra effort to place the newborn skin-to-skin soon after cesarean birth.

### Pro Tip



Even a minute or two of skin-to-skin contact can help a mother establish a lasting bond with her baby. If at all possible, consider allowing the newborn to rest, even momentarily, on her mother's chest. Research has shown many benefits of skin-to-skin contact, for both term and preterm infants, including cardiopulmonary stabilization at birth, improved thermoregulation, improved blood glucose regulation, and overall, improved breastfeeding rates and duration.



## Mom Tip

Remind your medical team that, if at all possible, you would like to have skin-to-skin contact with your baby right after birth.

If your hospital does not yet offer the opportunity for skin-to-skin contact after cesarean birth, ask if other options are possible. For example, you could request that a nurse bring your baby to visit you in the recovery room. This may not be possible unless your baby is in excellent condition, but it can be a good option for babies who are stable. Another suggestion would be for you to go from the operating room to

the NICU on your way to the recovery room. If your baby is not in the middle of a critical procedure, you could ask her nurse to place her on your bare chest as you lie on the stretcher. When you make these suggestions, make it clear that you understand that both you and your baby must be in good condition to do skin-to-skin contact.

What if skin-to-skin contact while your baby is wet and slippery does not appeal to you? This is perfectly understandable! Ask your nurse and obstetric provider to dry your baby quickly with a towel or blanket before placing her skin-to-skin with you. This way, you can fully enjoy the experience and all the benefits of skin-to-skin closeness.

Your birth experience will be unique and will include many components. We hope that one of those components is skin-to-skin contact, which improves a baby's temperature stability and may increase duration of breastfeeding. However, if you or your baby have difficulties that make it impossible to have this experience immediately after birth, all is not lost. Skin-to-skin care, or kangaroo care, as it is called in many NICUs, is encouraged and, regardless of when it is initiated, contributes to improved breastfeeding, milk production, parental satisfaction, and bonding.

## Questions to ask: getting involved in the plan

Here are some questions that you may want to include in your discussion about the initial plan for your baby's care. To make sure that there is time for a calm discussion, ask your questions and make your wishes known in the hospital well before your baby's birth is imminent. Review your wishes with each new practitioner so that everyone understands your goals, if possible.

- If my baby is doing well immediately after birth, it's important to me that she be placed skin-to-skin on my chest. Can that be part of our plan?
- If my baby is doing well, how long will she be able to stay skin-to-skin with me?
- I plan to breastfeed my baby. Can I offer my baby a chance to breastfeed during our initial skin-to-skin contact?
- How will you decide when or if my baby needs to be moved to the NICU for admission?

- Will my partner or family member be allowed to accompany the baby to the NICU?
- How soon will I be able to see my baby in the NICU?
- Is it possible for me to stay overnight in the hospital if I'm discharged and my baby is still in the hospital?

## Before you begin your NICU journey

After the initial excitement of giving birth fades and the reality of the NICU journey begins, you may feel overwhelmed. It may seem like people are giving you too much information. Don't worry if you cannot remember everything. The NICU staff expect to repeat and clarify information many times as you become familiar with the routines of the NICU and your baby's plan of care.

Try to do these things on your baby's birth day:

- Get some rest. Even a few hours of sleep will help you cope with the initial stress of the NICU.
- Let your nurse and your baby's nurse know that you plan to breastfeed your baby. If your baby cannot nurse at your breast after delivery, and if your medical condition allows, start expressing your milk within 1-3 hours.
- Eat and drink, as permitted. It may have been a while since your last meal. Hunger and dehydration, together with the big loss of body fluid that normally happens when giving birth, can lead to dizziness and fainting.
- Conserve your energy. You have just gone through a strenuous physical ordeal. Use a wheelchair to get from your room to the NICU.
- Inform those close to you of your baby's birth, if you choose, but resist the urge to entertain a parade of visitors. You will adjust to your NICU experience more smoothly if you allow yourself a few days to get familiar with your new routine. There will be plenty of time for your friends and loved ones to meet your new baby after she is stable and healthy.

## GETTING FAMILIAR WITH THE NICU

The NICU can be overwhelming at first, but as you learn to identify the sounds, understand the purpose of the equipment and technology, and begin to care for your baby on your own, you will feel more at ease. You are encouraged to ask your baby's nurses and medical providers the purpose of each piece of NICU equipment and why each procedure is being performed. Being educated about what is happening to your baby may help you feel more comfortable and in control.

## First steps

Your initial orientation to the NICU may include:

- Infection control practices, such as how to clean your hands before visiting your baby, the importance of using the disinfectant hand gel after you touch contaminated surfaces (for example, your cell phone), and other ways to protect your baby from infection, such as staying home when you are sick
- Home-away-from-home resources, such as overnight accommodations and parent lockers, (if available), the parent lounge, refrigerator and microwave, restrooms, device charging stations, pumping stations, and perhaps a library of NICU information

Your baby's nurses want to know about you, too. They may ask questions about:

- Your level of experience with newborn care
- If you've had previous experience in a NICU
- What you already know about your baby's plan of care
- Your plan for feeding your baby
- If you or your family members require the services of a medical interpreter
- How you would like to learn (for example, by talking one-on-one with a NICU team member, through written information such as a book or pamphlet, or by video/online resources)
- How to contact you when you are not present in the NICU

If your home is a distance from the NICU, or you will not be able to see your baby every day, the NICU nurses will suggest ways to keep you informed and involved in your baby's progress. Consider setting up a daily phone call to talk with a member of your baby's care team about the plan for the day, discuss what is going well, and review any changes or new information. Some NICUs offer an opportunity to periodically check on your baby by webcam. Check with your baby's care team to see if this option is available to you.



### Mom Tip

Consider carrying a small notebook to write down important information, including the names and roles of the people on your baby's care team. You will likely be exhausted after delivery and you may not remember events clearly. Keeping a notebook is a helpful way to remember whom you've met and to document important points about your baby's care.

Many NICUs require that you provide your baby's medical record number or other unique identifier before they give you information over the phone. If you have to leave the NICU, remember to write down this information and keep it in a safe place, such as your phone or wallet.

## If English is Not Your First Language

In the US, doctors often present the baby's parents with choices about their baby's care, and parents are expected to participate in making these decisions. It is vital that you understand information thoroughly and ask questions to better understand the decisions that you are asked to make. If English is not your first language, or if you are new to the United States, you may have trouble understanding medical information.

At your request, the hospital is required to provide a medical interpreter who speaks your language, free of charge. This service may be provided in person, over the phone, or through video chat. You can ask for a medical interpreter for every meeting with your baby's medical team or only when you are having trouble understanding, depending on your preference.

Even though it may seem easier, it is better not to use a relative or friend to translate. They may not understand fully the medical language and may make mistakes when interpreting. This could mean that you do not have all the information needed to make the best decision for your baby.

An interpreter who works with the hospital will correctly translate everything your baby's care providers are saying and will help them understand your questions and concerns. A medical interpreter can also help you with any forms and paperwork that you may need to fill out and can help the hospital staff understand any cultural needs you may have.

Think of your medical interpreter as an important part of your baby's medical team. They can help ensure that you and your NICU team are communicating effectively so that your baby receives the best possible care.

Updating multiple family members and close friends about changes in your baby's status can be an additional, unneeded burden to life in the NICU. Consider streamlining the hard work of keeping everyone informed by starting a private website such as *www.CaringBridge.com* or *www.PostHope.org* or by putting a trusted family member or friend in charge of updating others so that you may focus on your baby.

In the days following your baby's birth, take some time to review your labor and birth experience with a good listener. This could be your partner, a trusted friend or family member, your medical provider, or your nurse. If you had a complicated birth, or if your baby required lifesaving procedures, the entire event might seem unreal. It may be helpful to discuss the details of those events with your obstetric provider or your baby's medical provider. Having a clear picture of what happened and getting your questions answered will help you put the pieces of your experience into place and will allow you to cope better with the challenges of the NICU.

## TYPICAL NICU EQUIPMENT

The NICU is designed to achieve a delicate balance between close and careful observation and a reasonable amount of privacy for your new family. Some NICUs arrange all the babies together in a large area separated by curtains or short walls between the babies' cubicles. Other NICUs are built so that each baby has a private or semi-private room.

## Your baby's bed

A **radiant warmer** is a flat mattress with an overhead heating unit. This type of bed is frequently used immediately after birth for any baby, whether they will be transported to the NICU or not. It is open on three sides, making it easy for healthcare professionals to assess and monitor your baby as well as making it easy to perform any needed procedures.

An **incubator** is used for babies who need assistance maintaining their body temperature within a normal range. The incubator provides heat, and sometimes, humidity. An incubator is enclosed on all sides.

A clear plastic **bassinet** may be used for your baby if she can maintain her temperature within normal limits with only baby clothes, blankets, and, in some cases, a hat.



*Francis and Naima, who is only a few hours old, in an incubator.*

## Typical monitoring equipment

The specific equipment and monitors attached to your newborn will vary depending on the reasons your baby is in the NICU. It may take a while for you to get accustomed to the various pieces of equipment used for your baby, but soon you will know their purposes and the sounds they make.

A **cardiac monitor** is standard for most babies in the NICU until they near discharge. Several sticky patches (called **leads**) are applied to your baby's chest and abdomen and are attached to a cardiac monitor that displays your baby's heart rate and breathing rate. If your baby is very preterm, the patches may be attached to your baby's upper arms and legs (called **limb leads**). When a baby's heart rate or breathing rate is too high or too low, the cardiac monitor alarms so that a NICU team member can assess the situation.

A **pulse oximeter sensor** (sometimes called a **pulse ox** or **sat monitor** for short) may be wrapped around your baby's hand, wrist, or foot. This sensor lies on the skin and uses a red light to indirectly detect the amount of oxygen in your baby's blood. The pulse oximeter tells the NICU team if your baby is getting the correct amount of oxygen.

## Methods used for intravenous access

Your baby may require an *intravenous (IV) catheter* for fluids, nutrition, or medication. There are several different types of IV catheters, depending on your baby's needs.

A *peripheral IV* is placed in a vein very near the surface of the skin. This IV may be placed in your baby's hand, arm, foot, or, less commonly, in her scalp. A peripheral IV is used when it will be needed for only a few days. This type of IV is sometimes challenging to place in a baby's tiny veins, so your baby's nurse will carefully safeguard the IV from accidental bumping or dislodgement. A peripheral IV is fragile and may need frequent replacement. Even if your baby's IV is working fine, many NICUs have standards for how frequently they must be changed to prevent infection.

An *umbilical line* is a long thin tube (called a *catheter*) placed in the artery or vein of the umbilical cord. If placed into an artery, it is called an *umbilical arterial catheter (UAC)*. If it is in the umbilical vein, it is called an *umbilical venous catheter (UVC)*. An umbilical line is threaded into deeper vessels in the body and can be used to give your baby fluids and medication, and can usually be used to remove blood for laboratory testing. An umbilical line is used for babies with medical issues that require close monitoring and frequent blood tests.

A *peripherally inserted central catheter (PICC line)*—pronounced “pick line”—is inserted into the baby's arm or leg and threaded into a deep vessel. It is used when your baby will need an IV for more than a few days or if a peripheral IV is difficult to place for any reason.

## Alarms

Every effort is made to keep the NICU quiet so that babies can rest and grow. However, to ensure your baby's safety, NICU equipment and monitors are designed to alarm for many different reasons. For example, an IV pump may alarm to indicate that a medication has finished going into an IV, or a monitor may alarm to alert the provider that your baby's oxygen level or heart rate needs attention. These alarms alert NICU team members about possible problems so the situation can be evaluated immediately.

While alarms are disturbing, they do not always indicate a real problem. For example, the cardiac monitor or pulse oximeter can lose a reliable signal and sound an alarm when, in fact, your baby is just fine. In any case, a NICU team member will always respond to an alarm and make sure that adjustments are made, if necessary. If your baby is in the NICU for an extended period of time, you will probably learn to tell the difference between an alarm that indicates a change in your baby's condition and a false alarm.

## WHO ARE ALL THESE PEOPLE?

If your baby's NICU is in a teaching hospital (where trainees work under the supervision of an experienced clinician), you will often see unfamiliar physicians because the residents (physicians in training) circulate among different patients as part of their education. Even in NICUs with fewer staff, it will take some time for you to learn who everyone is and what they do. It is okay to ask NICU team members for their names and roles in your baby's care. Consider writing this information down to help you keep track of who's who.

### Key players

Every NICU is a bit different, but these are the key people in a typical NICU:

- **Neonatal nurse** – a registered nurse who specializes in the care of sick newborns. The neonatal nurse works in collaboration with the medical team and helps you prepare for your baby's homecoming.
- **Lactation specialist** – a breastfeeding expert who works with the NICU team to assist parents and babies with breastfeeding. If you have not seen a lactation professional within 24 hours after your baby's birth, request a consultation as soon as possible.
- **Social worker** – a professional who provides information and resources to NICU families about finances, community resources, coping with stress, and preparing for discharge.
- **Attending physician** – the doctor in charge of your baby's care. Often this person will be a neonatologist.
- **Neonatologist** – a doctor who has completed pediatric residency training and a fellowship in newborn intensive care. Most neonatologists work in a NICU and do not have an office outside the hospital where they see patients.
- **Fellow** – a pediatrician in a teaching hospital who is in training to become a neonatologist.
- **Resident** – a physician in a teaching hospital who has finished medical school and is now in a program focusing on a medical specialty such as pediatrics. Your baby may receive most of her care from the pediatric resident who is supervised by the attending physician and fellow.
- **Neonatal nurse practitioner (NNP)** – a registered nurse with an advanced degree and specialized training in the care of sick newborns. The NNP works in collaboration with the medical team and can prescribe medication and perform advanced practice procedures such as intubation (placement of a breathing tube into the airway) and umbilical line placement.
- **Physician assistant (PA)** – a medical practitioner who works under the supervision of a physician. Some NICUs have PAs on the medical team; their role is similar to the NNP's role in the NICU.



- **Respiratory care practitioner** – Also known in some hospitals as a respiratory therapist, this team member evaluates and monitors lung function and manages respiratory equipment and treatment.
- **Speech-language pathologist (SLP)** – a specialist who evaluates and treats patients of all ages who have difficulties with speech, language, and swallowing disorders. Sometimes an occupational therapist (OT) serves in this role for infants with oral motor issues.
- **Discharge planner** – a hospital staff member who coordinates resources with the rest of the NICU team to help ensure that you and your baby are prepared for discharge in an organized manner. The discharge planner may be a nurse, social worker, or a specially designated employee who is familiar with the needs of babies and families in the NICU and after discharge.

Depending on your baby's specific needs, she may also see other pediatric specialists. All of these doctors have finished a pediatric residency and have had training in their specialty fields. Some examples are: a **cardiologist** who specializes in the function of the heart; a **gastroenterologist** who specializes in issues of the gastrointestinal tract; an **otolaryngologist** (also called an ENT) who specializes in issues of the ear, nose, and throat; a **pulmonologist** who specializes in lung disorders; a **neurologist**, who specializes in issues of the brain; or an **endocrinologist**, who specializes in glands and hormones.

Everyone who comes to your baby's bedside should wear a visible nametag, introduce themselves, and tell you their role (resident, attending physician, nurse, etc.). If you are in the NICU often or for extended periods of time, you will soon recognize faces and feel comfortable with many of the staff members. However, if someone is caring for your baby without an introduction, do not hesitate to ask for the person's name and role in your baby's care.

## LEARNING ABOUT YOUR BABY'S CARE

Knowledge is power and helps to increase your sense of control in the NICU. If learning about your baby's care makes you feel less stressed, you can take steps to understand the reasons your baby is in the NICU, the terminology used during discussions about your baby, and what must be accomplished before she can go home.

## Learn about the problems and the terminology

Ask your baby's doctor or nurse for trustworthy resources about the NICU and typical problems babies in the NICU sometimes face (see appendix for additional resources). It might be helpful to learn the terminology and as much as you want to know about your baby's diagnoses and treatments. You certainly do not need to know as much as the healthcare team about your baby's diagnoses, but knowing the basics will help you understand the reasons for various treatments and will allow you to advocate more effectively for things you believe are important.

## Attend patient rounds

Most NICUs invite parents to participate in patient rounds. This is when members of the NICU team get together, usually on a daily basis, to review each baby's progress and create a plan for the next steps. Rounds ensure that all of your baby's care providers have the most recent information and that steady progress is being made toward discharging your baby from the NICU.

Some NICUs encourage parents to ask questions and provide input during patient rounds; other NICUs encourage parents to listen during rounds and ask their baby's doctor questions after rounds are over. Especially in NICUs with many babies, asking questions specific to your baby after rounds is often the most efficient use of everyone's time.

Some parents are shy about attending rounds or are afraid of asking a silly question; however, you can learn a lot about NICU care and about your own baby's specific plan of care by attending rounds. You know your baby better than any member of the NICU team, and your input about the plan of care is important. Being at rounds when your baby's care is discussed may give you the opportunity to talk to the NICU team for a few minutes and to participate in decision making. Consider taking a notebook to record details of your baby's care so that you can refer back to the information, if needed. Ask your baby's care team what goals need to be met before your baby can go home and how you can participate in the care plan to help your baby meet those goals.

If you cannot participate in rounds, ask the nurse caring for your baby to contact you at some point after rounds every day to update you on your baby's plan of care. You could ask your care team if it is possible to participate in rounds by phone. This keeps you informed and helps you understand what is involved in the steps needed to reach a goal. This understanding will also help you appreciate the reasons why your baby's plan of care may change.

## COMMUNICATING WITH THE NICU TEAM

You are a valuable partner in your baby's care. One of your most important goals is breastfeeding your baby. Reading this book will help you understand the challenges you and your baby may face when attempting to breastfeed. It will also help you develop strategies to overcome those challenges so that you will have a successful, healthy breastfeeding relationship with your child. Communicating your intentions with your baby's healthcare team is essential to meeting your breastfeeding goal.

### Conversations that invite input and collaboration

Your NICU team welcomes your questions and suggestions and will go the extra mile to work with you to meet your goals. Knowing how to start conversations that encourage collaboration is an important skill that will help you meet those goals. For example, instead of beginning conversations with phrases such as, "I want you to..." or "You may not be aware of this research, but..." try a gentler approach. Beginning with a question instead of a demand can promote teamwork and communication with the NICU staff. It may help to remember that both you and your baby's NICU team have the same goal: a safe and healthy discharge home for your baby.

### Communication Starters

Starting your questions or ideas with conversation openers can help you reach your goals. These openers allow you to give and receive information at the same time.

"Would you think about...?"

"Can you share with me the pros and cons of...?"

"What if we tried...?"

"I read about...Do you think that might work?"

"I'm not familiar with...Can you tell me more?"

From Zaichkin J, editor, *Understanding the NICU: What Parents of Premies and other Hospitalized Newborns Need to Know.*

Elk Grove Village, IL: American Academy of Pediatrics; 2017:138.

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## Make an appointment

The NICU environment is fast-paced and the workload changes from moment to moment, so your baby's care provider may only have a few minutes at a time to speak with you during a busy work shift. If you need more than a few minutes to speak with your baby's doctor, ask for an appointment to meet on a specific day and time. If your baby seems to have many doctors that come and go, ask for the nurse's help in making an appointment with the attending physician (usually the neonatologist). Setting a meeting time helps ensure that your baby's care provider will be able to spend more time with you and can prioritize your needs during a conversation.

## Request a care conference

If you have many questions for different members of the team (physician, lactation consultant, nurse, social worker, discharge planner), you may ask your baby's nurse to request a care conference. This meeting gathers everyone together to answer your questions, address your concerns, and help you learn about your baby's plan of care. A care conference is different from daily rounds because it is a scheduled meeting focused only on your baby. This allows more time for your baby's care team to review what progress has been made and the milestones they hope that your baby will meet before discharge.

## Write down questions and keep a journal

When your baby is in the NICU, you are busy learning about her care. You also may be responsible for other children, taking care of your own needs, and keeping your household afloat. It's no wonder that you may not be able to remember the questions you want to ask when you get the opportunity. Keeping a journal about what happens in the NICU and writing down questions as you think of them can be very helpful. You can use a paper notebook or a digital device, such as a phone or tablet, to make note of your questions and the answers you receive.

## GETTING TO KNOW YOUR BABY IN THE NICU

Parenting in the NICU can be challenging. The lack of privacy, the worry and loss of control, and the wires and tubes can interfere with bonding and attachment. As your baby makes progress and you become more comfortable in the NICU, many of these challenges become manageable. In the meantime, consider these strategies for getting to know your baby.

## Touching and holding

If your baby is critically ill, and if holding her in your arms would put her at risk for low oxygen or might dislodge lifesaving equipment, you must wait for her to improve before holding her. The NICU team will tell you when it's safe to hold her, and they will help you do so as soon as possible.

Even if you can't hold your baby right away, you can touch her. You will soon learn what kind of touch your baby prefers. Most babies, especially preterm infants, enjoy a firm touch more than a tickly light touch. Try holding your warm hand on top of your baby's head or cradling her feet in your hands. Your baby's nurse can show you how to provide these comforting touches.



*Ryan, only a few days old, nursing with oxygen in place.*

If a pulse oximeter, cardiac monitor, intravenous tubing, or feeding tube is connected to your baby, it can be challenging to hold and cuddle her. Most NICU nurses will help you manage the tubes and wires and will encourage you and your partner to hold your baby with some equipment in place. At first, the nurse will stay close to make sure your baby is doing well and that you are comfortable. Eventually, the nurse will help you get settled with your baby but will remain nearby in case you need assistance. As your baby requires less equipment and has fewer tubes and wires, you will need less of the nurse's help to hold your baby.

If you are in a large room with other families, you may feel a bit exposed as you get to know your baby. It may help to know that other parents are much more focused on their own baby than on what you are doing. You can increase your privacy by closing the curtains around your baby's area if possible, and by turning your chair away from the activity in the room.

## Skin-to-skin care

Practice skin-to-skin care, also known as kangaroo care in some NICUs, whenever possible. Skin-to-skin care is not only a great way for you and your partner to enjoy closeness and bonding with your baby, but it also promotes a longer duration of breastfeeding and increases milk production. Skin-to-skin care has also been associated with increased parent satisfaction, better sleep organization for the infant, including longer duration of quiet sleep, and decreased pain perception during procedures.

Kangaroo care is not for mothers only! You or your partner can hold your baby skin-to-skin whenever possible. To practice kangaroo care, wear a shirt that opens in the front for easy positioning. Before starting skin-to-skin time, the nurse will have you sit in a comfortable chair with pillows for back support. Your baby wears only a diaper. The nurse will place your baby skin-to-skin on your chest, making sure that your baby's head stays in an upright position with her face turned to one side for safe and easy breathing. The nurse will place a blanket, or your clothing, over you and your baby so that your baby can stay warm while you both enjoy skin-to-skin contact for as long as you and your baby are comfortable.



*Edward and Julia Grace, who is less than 24 hours old, practicing skin-to-skin contact.*

If your baby shows interest, allow her to nuzzle your breast. Your baby's nurse may dim the lights to encourage your baby to open her eyes. Most full-term babies will become alert to your voice, look at you, and enjoy the warmth of skin-to-skin contact. If your baby is very premature, being held, spoken to, and maintaining eye contact all at the same time or in quick succession may be too stimulating. Your baby's nurse will teach you to read your baby's stress cues so that you can offer stimulation one step at a time.

## **NESTING: MAKE YOURSELF COMFORTABLE**

The NICU may be your home away from home for a while. You can make yourself more comfortable by personalizing your baby's space and your place within it—in other words, make yourself a little nest.

If your baby has a private room, you may have ample space to bring personal items and leave them in her room. For example, you may be able to bring a decorative pillow or a favorite quilt for the pullout sleeper chair or sofa. You may be allowed to stock a few favorite snacks in a cupboard. However, do not leave any valuable or irreplaceable items in your baby's space. If you would be very upset at an item's disappearance, leave it at home.

Ask your baby's nurse what is allowed in and around your baby's bed. Where can you put photos of you and your family members and pets? Is there space for a picture that an older sibling drew for their new baby sister? If you can have photos, consider also posting an affirmation that helps keep you positive or reminds you of your goal.

Dressing your baby in clothes that you bring from home may help encourage a sense of normalcy and may help you bond with your baby. Ask your baby's nurse if it's okay to do this and request recommendations for which types of clothing will allow your baby's care team access for procedures, if needed.

## TAKING CARE OF YOURSELF

The NICU can be a stressful experience and you must take care of yourself. If you are exhausted, it is more difficult to heal from childbirth, produce breast milk, and cope with the stress that is inevitable during a NICU experience.

### Take a break

Your baby's care team does not expect you to be at your baby's bedside 24 hours a day, 7 days a week, nor is it healthy for you to do so. It's important to take a break away from the NICU once in a while. Go on a date with your partner, spend time with your other children, or simply go home. Ask a trusted friend or family member to supervise your other children and take a relaxing bath, read a magazine, or take a nap in your own bed.



### Mom Tip

Your top priorities are your own rest and recovery and keeping your baby calm and healthy. If you do not feel up to entertaining visitors, it is okay to let them know that there will be plenty of time to meet the new baby after she is discharged from the NICU.

### Baby blues

Baby blues are normal after giving birth, but mood swings, sadness, and irritability should diminish after a couple of weeks. If you continue to have these feelings, or if you experience worsening symptoms such as anxiety, guilt, hopelessness, poor sleeping, lack of self care (not bathing or grooming yourself), persistent fear for your baby's life, or have thoughts about harming yourself or others, please seek immediate professional help. Postpartum depression, and even post-traumatic stress disorder (PTSD), are very real possibilities for NICU parents (both men and women) and your concerns will be taken seriously. Don't wait and suffer in silence. Speak with the NICU social worker, your obstetric provider, or your family practitioner about your symptoms so that you can get treated and be the best possible parent to your baby.

## What to Bring

A tote bag is a convenient way to bring items to and from the hospital to visit your baby. Consider bringing the following items with you to make your NICU stay more comfortable:

- A favorite book or magazine to help you relax when you have some downtime.
- Your favorite beverage or a few tea bags, snacks, and fruit.
- A journal or notepad and extra pens to write down your thoughts and feelings during this transition period and to keep notes about your baby's medical condition, her medical team, and other important information.
- Digital music and headphones.
- Your cell phone and charger.
- A tablet or small laptop and charger.
- Comfortable clothing, loose-fitting pajamas, a bathrobe, slippers, or flip-flops for those middle-of-the-night visits (if you are spending the night).
- Basic toiletries such as a toothbrush and toothpaste, comb, and deodorant.
- Feminine care products (pads) and an extra pair of underwear, just in case.
- Prescription medication and whatever you usually take for aches and pains (you may be sore after giving birth). Make sure you check with your doctor to ensure any medication you are taking is safe for a nursing mother.
- Your most comfortable bras because your breasts will be tender while your milk is coming in.
- Small comfort items like mints, lip balm, quality tissues, and your own hand soap and lotion.
- Your own pillow with a distinctive pillowcase so that housekeeping staff knows that it's not a hospital pillow.
- A small cloth or article of clothing that smells like you to leave with your baby when you cannot be there (check with your baby's nurse about this).



## WORKING TOWARD THE GOAL OF BREASTFEEDING

In the NICU, you have the advantage of being surrounded by healthcare professionals who understand the benefits of breast milk and want to offer information and resources to help you be successful. Take advantage of this support and use the expertise offered to you.

### Early nutrition

Some babies cannot eat anything by mouth when first admitted to the NICU. These babies receive nutrition through an IV to ensure that they have enough fluid and glucose (sugar) for hydration and energy.

Babies with Down syndrome sometimes do not have the coordination to suck, swallow, and breathe while feeding at your breast or from a bottle. Being able to coordinate these three actions is crucial to successful oral feeding. If your baby has similar issues, she may need to receive breast milk through a tube that goes through her mouth (orogastric tube) or nose (nasogastric tube) and into her stomach, called a *tube feeding* or *gavage feeding*. Most babies who start their lives in the NICU have used a combination of feeding methods, by tube, bottle, and/or breast, before being able to get all their nutrition at the breast (see chapter on tube feeding or more information).

If your baby is in the NICU, you will probably need to express breast milk and store it in the NICU refrigerator or freezer. Your NICU nurse will teach you about pumping breast milk at the hospital or at home and safely transporting it to the NICU. Your NICU nurse or lactation specialist will show you how to use the breast pump, clean it afterward, and label and prepare your breast milk for storage in the refrigerator or freezer. Ask your baby's nurse to provide you with labels that have your baby's name and medical record number on them to make labeling your breast milk easier (see the chapter on pumping for more information).

### Religion and Use of Donor Breast Milk

If you practice Islam or Judaism, there may be cultural and religious issues to consider before you decide to use donor breast milk. Your faith leaders can provide you with more information and help you make a decision about using donor milk.

### Will you use donor breast milk?

The American Academy of Pediatrics recommends that preterm infants receive mother's milk during a NICU stay, but donor milk (also called banked human milk) is a suitable alternative when mother's milk is not available. In NICUs in the United States, donor milk comes from milk banks that follow the safety and quality guidelines established by the Human Milk Banking Association

## Giving Your Baby Colostrum for Oral Immune Therapy

If your baby is premature or unable to breastfeed because of a medical condition, you may still be able to give her your **colostrum**, the breast milk produced in the first few days after giving birth.

Colostrum is especially rich in nutrition, growth factors, and immune cells. Colostrum for oral immune therapy (C-OIT) is standard practice in many NICUs for sick and premature babies. The colostrum given to your newborn for oral immune therapy is not meant to feed her. The benefits of oral immune therapy are still being studied, but it is thought that oral immune therapy helps to:

- Decrease the time needed for the baby to progress to full oral feedings
- Stimulate the baby's immune system and reduce the risk of infection
- Reduce the length of hospitalization

Colostrum collection can be challenging because this early milk is thick, and you may be able to collect only a few drops at a time. Don't be discouraged! Every drop is important. The most effective way to express colostrum is by hand. To do this, your nurse or lactation consultant will help you sit up or lie on your side. Using your hands, massage your breast in the direction of the nipple until a drop of colostrum is visible. Your nurse may use a small food grade syringe to suction the colostrum off your nipple, or you may be able to drip colostrum into a small medicine cup. You may be asked to collect colostrum every three hours. As your milk production increases, you will use a breast pump for collection.

Colostrum is administered as oral immune therapy in various ways. Sometimes, administration is done by giving your baby a few drops of your milk between her cheek and gum and allowing it to absorb through her mucous membranes. The colostrum is

usually administered with a small syringe (with no needle). Another method involves soaking a sterile cotton swab with your colostrum and wiping it onto the baby's tongue, gums, and inner cheek. Oral immune therapy with colostrum may be done as frequently as every three hours. Your baby does not need to swallow to receive the potential benefits.

Check in with your baby's medical team before your due date to discuss the potential benefits of oral immune therapy for your baby, especially if you are likely to have a preterm baby. Soon after your baby is born, your hospital's lactation consultant or your nurse can help you to hand-express or pump your colostrum and collect it in a small syringe for this purpose. Ideally, your baby will begin this important treatment within six hours of her birth.

Even though more study is needed to produce strong evidence about the benefits of colostrum as immune therapy, it poses little risk to infants and encourages you to begin expressing your milk very early in the NICU stay. This in itself is an important contribution from you to your baby in the NICU.

of North America (HMBANA). If your baby's healthcare team determines that your baby would benefit from human donor milk, you will be asked to sign a consent; then your baby's medical provider will write a prescription for the donor breast milk.

In the US, donor breast milk comes from a variety of sources including HMBANA and others. Donors are unpaid volunteers who are screened for transmissible diseases. The milk is gently *pasteurized* (heat treated to kill viruses and bacteria), tested for bacterial growth, frozen, and shipped to hospitals.

If you are having trouble providing all of the breast milk your baby needs and if prescription donor milk is not an option, you may be tempted to engage in *milk sharing* (receiving milk from friends or from strangers on the internet). However, it is advised only to use donor milk provided through a human milk bank that follows HMBANA guidelines to ensure the highest quality. The risks of milk sharing include:

- **Bacterial contamination** – Bacterial contamination can occur due to improper collection or transportation methods.
- **Viral contamination** – Certain viruses can be transmitted through human milk, including HIV and hepatitis. A donor mother may not know that she has these viruses. Unfortunately, infants are more vulnerable than adults to these viruses, and the side effects of some of these viral infections may not be evident for several years after exposure.
- **Substance contamination** – It is common for human milk purchased online to contain cow's milk or infant formula. In addition, shared milk will contain whatever substances the donor mother has ingested, including nicotine, alcohol, and prescription medications, supplements, or illegal street drugs.

Visit [www.hmbana.org](http://www.hmbana.org) to learn more information about pasteurized human donor milk.

## STRATEGIES FOR REACHING YOUR FEEDING GOALS

This book is filled with information to help you reach your goal of breastfeeding. To summarize, here is a list of strategies to consider during your NICU journey:

- Tell your baby's medical team that you want to breastfeed your baby.
- Begin expressing your milk as soon as possible after your baby's birth, ideally within one to three hours, if your condition permits.

- Make an appointment to meet with a lactation consultant as soon as possible after NICU admission, ideally within 24 hours. Find out how to contact her with questions or for assistance. Ask how often she discusses your baby's feeding plan with your medical team and how you will be updated on the plan. If you attend rounds or talk daily with your baby's nurse or medical provider, you will receive frequent updates about your baby's feeding progress and plan.
- For pumping at home, rent a high quality, fully automatic electric breast pump (sometimes referred to as hospital-grade) that pumps both breasts at the same time. Your insurance or Medicaid may cover this expense. Ask your social worker if you need assistance finding out about this.
- Ask your NICU nurse or lactation specialist how to store milk at home, how to label it, and how to transport milk to the NICU.
- Practice skin-to-skin care (kangaroo care) daily, if possible.
- Consider requesting a consultation with a speech-language pathologist (SLP) who specializes in feeding issues. SLPs often work with lactation consultants and will assess your baby's feeding and swallowing and will work to develop an individualized feeding plan for your baby.
- The American Academy of Pediatrics recommends that mother's own milk is best for preterm infants in a NICU, but donor milk (also called banked human milk) is a suitable alternative when mother's milk is not available.

## LEARN FROM YOUR NICU EXPERIENCE

While no parent would want their baby to spend time in the NICU, there are advantages. You and your baby will have the opportunity to learn about one another while surrounded by baby experts who have devoted their entire careers to the health of children. You will learn what is most important about your baby's care and how to communicate effectively with your baby's healthcare team.

When your NICU stay is over, you may not have achieved every goal that you had in mind, but you will have made progress and you will have a better understanding of how best to meet challenging goals in different ways. This knowledge is powerful and will serve you well as you continue a life of advocacy for your child.

## Mom Story

### ERIKA & EDEN



From the moment I decided to have children, I knew that I wanted to breastfeed. As far as I was concerned, there was no other option. I never thought about any complications that could stand in the way of a beautiful, natural birth ending with my two perfect babies nursing happily away.

The moment I had the first excruciating pangs of labor, I knew it wasn't going the way I planned. Instead of the beautiful natural birth I'd hoped for, I needed a c-section. One of my babies was much bigger than we expected, and the second one was much smaller. The first was allowed to go to my hospital room with Daddy; the second was taken to intensive care.

When I finally got out of recovery, only one baby, Evan, was waiting for me. We bonded immediately, intensely. He started to nurse, and everything was perfect except for the absence of his twin.

When I finally saw my second baby, Eden, it had been more than five hours since his birth. I remember how small

and full of tubes and wires he was. I was afraid to hold him. They told me there was a good possibility he had Down syndrome. I knew that was true when I saw him. In a haze, I asked about giving some milk to him. Wasn't it important? A nurse helped me hand express a few drops. That was it?

The first few days that followed were terrible, as I had excruciating pain/complications due to the c-section. I had a hard time nursing Evan, who stayed in my bed and with whom I had now formed an incredible bond. Nursing HURT LIKE HELL. And all he wanted to do was nurse for hours at a time. I continued pumping for my little Eden. I was so overwhelmed and struggled to accept the news. Whether or not I would be able to nurse him was the last thing on my mind, but I wanted to at least provide him with my milk.

A few days later, I was feeling better and doing my best to bond with this tiny little baby who was still a big jumble of tubes and wires. I tried skin-to-skin contact, but I was terrified that I

*ERIKA & EDEN (CONTINUED)*

would pull out a wire or hurt him. He hardly opened his eyes, was very limp, and showed no signs that he knew I was holding him. I was heartbroken. While I was trying so desperately to bond with this child, another one was waiting impatiently to be fed.

When the speech therapist came to examine Eden's mouth, she asked if I wanted to try to nurse him. I was OVERJOYED! His little mouth was smaller than my nipple. We put his mouth next to it and waited. She put my nipple against his lips and moved it around; we waited more. Much to my surprise, he opened his mouth and accepted my nipple! He was weak but managed to drink the tiniest bit.

I stayed a week in the hospital and then was released with only one baby. Eden was struggling with a few serious issues, along with being very small, and couldn't come home with us. Over the next month, I pumped like crazy for Eden so he wouldn't have to be given formula. We made daily trips to the hospital to drop off milk and see him. I was still struggling to bond with him and was so relieved when he could finally come home and join the rest of his family. I ended up giving Evan formula because I just didn't have enough milk for both. Accepting that and then having to choose which child had priority to receive my milk was very depressing. Eden got priority for a long, long time, while Evan had a mix of breast milk and formula. I am extremely proud of how long I was able to provide Eden with only breast milk, and I'm positive it's the reason he's so healthy.

In the meantime, breastfeeding Evan was excruciatingly painful, and no nipple shield or cooling pads could help. I refused to give up. Nursing Eden was something I refused to stress about as long as I could keep pumping for him. We tried and tried, but it was so much work for him, and his stomach could not handle the amount of milk that came out. We switched breasts to the one that had less milk, and that became Eden's boob.

Every time I thought it was going great, he would nurse well, but afterward, he would throw all of it up. It was so discouraging to see all that milk go to waste, and I began to try less and less. After about two months, nursing started to go better, and I was finally bonding with my little guy. At last, after three months, Eden's stomach seemed to be able to hold down my milk! From that point on, Eden became an avid nurser, and I even managed to tandem nurse them!

Evan and Eden nursed for three-and-a-half years. They needed it, I needed it, and, for me, there is no purer feeling of love than looking down at a gorgeous little child who's fallen asleep nursing in your arms and knowing how difficult it was to get to that place. Stopping took months because I just couldn't bring myself to say, *it's finished*. It's been a few months now, and I still miss it. Despite the rocky start, I'm so head over heels in love with this amazing child and so grateful to have him and to have been able to nurse for so long.

## Mom Story

### CHARVEL & ISAAC



Isaac was born at 29 weeks and 5 days. He had intrauterine growth restriction (IUGR) and low diastolic blood flow. He was delivered by emergency cesarean section and went directly to the NICU. Amazingly, he did let out a cry after he was born. My husband said Isaac stopped crying and reached out to me when I spoke to him. It was midnight as I sat in recovery after being stitched up. They wheeled my son in his incubator toward my bed, and my little baby wrapped his fingers around the tip of my finger. The blessing of technology and medicine to help these little fighters continue to grow is an answer to prayers. At 3 a.m., while I was still partially numb, a lactation consultant came into my room and talked to me about pumping and colostrum, and she helped me hand express for the first time. We saved a few drops, and the next day, a few more.

Quickly and amazingly, my body responded, and soon I was asking for larger syringes to save milk. Before long, I was able to pump eight times a day. I wanted to hold my baby for the first time, but we had to keep his back straight, so we could not try kangaroo care yet. He weighed only 2 pounds and 3 ounces.

We learned that Isaac had Down syndrome almost four weeks after he was born. The neonatologist saw facial markers and suggested that we run a blood test. It came back positive, showing an extra copy of the 21st chromosome in all of his cells.

Breastfeeding was a struggle. Isaac's medical team placed a nasogastric (NG) tube not long after he was born, but we tried to breastfeed as soon as we could. I used a nipple shield, and Isaac could get latched after a few minutes, but it wasn't consistent. There were so many struggles: holding this little baby with tubes and wires, weighing him to see if he took anything by mouth and feeling disappointed that he didn't take more, his fatigue. He was always so tired. A lactation consultant met with me once a week in the NICU to help with breastfeeding and to encourage my pumping. Thankfully, I had more than enough milk for him. We worked with bottle feeds, all with my expressed milk. He had successes and setbacks in the NICU, but ultimately, breastfeeding became frustrating and wasn't as much of a source of bonding as I was told it would be. His fatigue continued, but the need for him to feed by mouth was important. We were instructed to push him to feed by mouth with bottle or breast even through his tiredness. He would have good days and not-so-great days. Most feeds during the day were with the bottle since he took more that way. He needed to get up to 70% of his intake by mouth before they would let him go home.

*CHARVEL & ISAAC (CONTINUED)*

Unfortunately, he got used to the flow of the bottle and would be frustrated at the breast due to lack of flow. I would hand express to fill the shield or would fill it with a syringe, and that helped some. It still was not enough.

Isaac worked to develop the skills needed to drink by bottle, and then I got sick and was not able to see him as much as I would have liked. Instead of getting him to breast once a day or every other day, it became only once a week. I did kangaroo care at least once a day while he was in the NICU. He was improving and was SO close to an ad-lib feeding plan (eating when he wanted instead of on a schedule), when he began aspirating (sucking fluid into his lungs) while eating and developed pneumonia. Suddenly, because of the fear that he would continue aspirating, his feeding plan was turned upside-down, and we could only feed him if he was awake and showing signs that he wanted to eat. At any sign of distress, we had to stop. Isaac's medical team approached us about placing a gastrostomy tube (also called a G-tube). We decided that the G-tube was the answer to Isaac's feeding issue, and that it might be the only way to bring our baby home. We transferred hospitals, and two days later, he had the surgery to place a G-tube. Four days after that, on Christmas Eve, we took Isaac home.

I continued to pump eight times a day, one still at 3 a.m. After the whirlwind of the holidays, I tried to bring Isaac to breast again a few times. There was only one good time. It was five minutes long, but then he fell asleep drinking milk, and I then gave him my pumped milk through his G-tube. Our lactation consultant wanted to use a nursing supplementer, but he and I were both frustrated, so he never latched. I wish I had tried harder to get him to breast, but I pumped for him. It was hard because I just wanted to hold him, but I had to pump. I never figured out how to do both at the same time.

I know that my son getting his G-tube kept us from having to go back to the hospital for one thing or another. The idea of breastfeeding became a thing of the past since our goal was to make feeding a positive experience, but breastfeeding was not a joyful time for Isaac or for me. I did feed my baby at least some of my milk until he was 10 months old. I pumped in my car, on an airplane, in an airport, in many doctors' offices, in the lactation offices, waiting rooms, and other people's homes. At around six months he was eating more than I could make, so we added formula. Eventually, the ratio of formula to breast milk increased and, as my supply dwindled, we transitioned to formula.

Looking back now, I am glad that I was able to give Isaac my breast milk. It was SO much work to pump milk for him. I wish that actual breastfeeding had worked, and that his NICU team had pushed breastfeeding more than bottle feeding. I wish I could have given him my milk longer, but I was able to bond more with Isaac after I stopped pumping. My breast milk was so good for Isaac, and he grew well for being a preemie. Isaac is now 20 months old, 20 pounds, and 31 inches tall. He still has a feeding tube and was 90 percent tube-fed for a while, but in the last two months, he has been eating all his pureed food by mouth. He is a joy-filled, curious little boy.



## Mom Story

### JESSICA & DJ



Danny Jr. (“DJ”) was born July 20th, a day before his due date, at 8 pounds, 9 ounces. I was able to hold him for a few seconds before he was whisked off to the NICU. When I was 13 weeks pregnant, we found out through chorionic villus sampling (CVS) that DJ had Down syndrome. After we found out, we toured the Neonatal Intensive Care Unit (NICU) and had a consultation with a NICU nurse even though we were hoping we would avoid spending time there. However, DJ was born with acute pulmonary hypertension, and we were told that his lungs were not pumping in the right direction. The treatment for this would require sedation, and I could not hold DJ at that time. What I could do was pump, so that when DJ was ready, he would have a supply of my milk to help him get stronger. The first few days I was able to give DJ oral colostrum to help his immune system.

The first week DJ was very sick, but once they were able to reverse the pulmonary hypertension, he was more awake and we began to try breastfeeding. At first, he had a hard time latching. We had help and support from lactation specialists and nurses. They encouraged us to try different positions, stimulating his palate, but the most successful tools were the nipple shields. We kept trying to get him to breastfeed successfully, but most of the time I continued to pump. We always started every feeding with a bottle or breastfeeding, and the rest of what he needed to grow was given through his NG tube. I produced more breast milk than DJ could use, so I built up quite a supply. We were told by DJ’s medical team that in order for him to be released from the NICU, he first had to take in enough calories orally with a bottle or breastfeeding.

I wanted DJ to get the benefits of breastfeeding, but I also wanted DJ to come home with us. I felt like those two desires were in conflict with each other. I was beginning to feel like the only way to get home was to have DJ bottle fed. Following a swallow study, the speech-language pathologists were concerned that DJ might be aspirating (inhaling breast milk into his lungs instead of swallowing it). The test showed that DJ could handle the thicker formula better than the breast milk from the bottle. Unfortunately, they could not observe how he handled breast milk from the breast. I sat with the team and discussed my concerns. I wanted DJ to be breastfed but I did not want him to aspirate. The nurses and lactation specialist said they knew that DJ could be a breast fed baby and encouraged me not to give up. We continued to breastfeed, bottle feed with the thicker formula, and use the NG tube, as needed. DJ did indeed figure out how to breastfeed and was able to get enough using a nipple shield. He began steadily gaining weight, and on August 20th, we were able to take him home.

When DJ was a year old, we found out that he had a tongue-tie, which could have made breastfeeding difficult. We also found out that DJ had laryngomalacia, which can also make feeding difficult. Even with these obstacles, DJ was still able to breastfeed successfully. DJ is healthy, growing, and he loves to eat! He is the joy of our lives.

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*Amy feeding Finley at the breast with a nursing supplementer*



## Heart Conditions

RACHELLE LESSEN, MS, RD, IBCLC, LDN

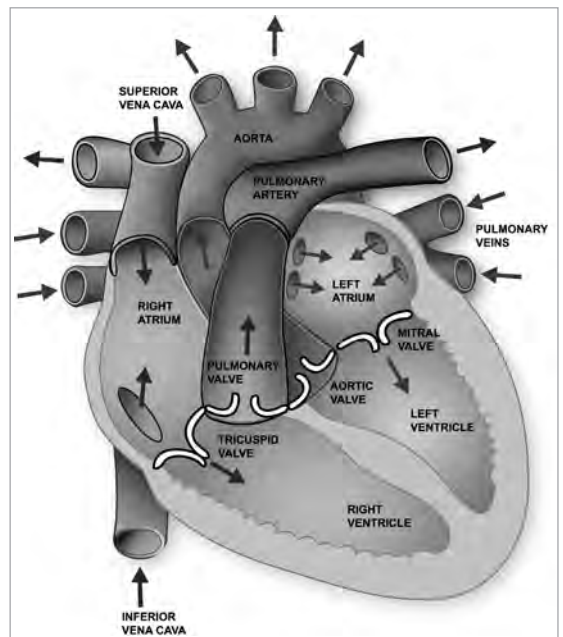
It's estimated that 40-60% of babies with Down syndrome (DS) will be born with one or more **congenital heart defects** (CHD). A congenital heart defect is a problem with the heart's structure that is present at birth and can change the normal flow of blood through the heart. The terms "congenital heart defect" and "congenital heart disease" are used to mean the same thing but "defect" is a more accurate way to describe a condition where the heart or the blood vessels near the heart do not develop properly before birth. Heart defects are the most common medical complication in infants with Down syndrome. In recent decades early diagnosis and treatment for these cardiac defects have greatly improved so that more babies are surviving into adulthood. If your child is born with a heart defect, identifying and treating it early is the best way to reduce complications and improve outcomes. Therefore, the American Academy of Pediatrics recommends routine cardiac screening for all newborns with DS. Sometimes, these heart defects can even be identified with a prenatal echocardiogram.

## COMMON HEART DEFECTS ASSOCIATED WITH DOWN SYNDROME

There are four chambers of the heart: the right and left atria (upper chambers) and the right and left ventricles (lower chambers). The heart and lungs work together to add oxygen to the blood. Blood returns from the body to receive oxygen by flowing into the right atrium, where it passes through the tricuspid valve into the right ventricle. It then passes through the pulmonary valve into the pulmonary artery and into the lungs, where oxygen is added to the blood. Blood with oxygen then returns to the heart from the lungs through the pulmonary veins into the left atrium. From there, it passes through the mitral valve into the left ventricle and through the aortic valve into the aorta, where it is pumped into circulation to the rest of the body. A congenital heart defect of any structure in the heart, valves, or vessels can impact normal blood flow to and from the heart, and to and from the lungs, resulting in poor oxygen delivery to the rest of the body.

No one is sure of the exact reason why there is such a high rate of CHD among infants with DS, but there is likely a genetic component because some heart defects are more common in children with DS than in other children. The most common heart defects found in children with DS are:

- **Atrioventricular Septal Defects (AVSD)** – An AVSD is a hole in the wall of both the upper (atria) and lower (ventricles) chambers of the heart. Sometimes the valves between the upper and lower chambers are also formed incorrectly.
- **Atrial Septal Defects (ASD)** – An ASD is a hole in the wall of the upper chambers (atria) of the heart.
- **Ventricular Septal Defects (VSD)** – A VSD is a hole in the wall of the lower chambers (ventricles) of the heart.



*The typical function of the heart*

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## BREASTFEEDING A BABY IN HEART FAILURE

Often a baby's medical team will want a baby with a heart condition to be fed through a bottle, but you should know that there is no evidence that breastfeeding is more work or burns more calories than bottle feeding. In fact, studies have shown that babies with CHD have improved oxygen saturation and heart rate while breastfeeding when compared to bottle feeding. Babies with CHD may need smaller, more frequent feedings per day to receive enough milk to grow.

### How to increase breastfeeding success

If your baby is having difficulty latching or transferring milk, it may be helpful to get breastfeeding assistance from an International Board Certified Lactation Consultant (IBCLC). Using a nipple shield may improve milk transfer if your baby's suck is weak or if he has trouble maintaining a deep and effective latch on the breast (see anatomical variations chapter for more information on how to use a nipple shield effectively). A *nursing supplementer device*, which is a thin tube that attaches to your breast and provides additional milk while your baby nurses, can increase the amount of milk your baby gets at each feeding. The benefits of using a supplementer include keeping your baby interested in breastfeeding, improving his efficiency, increasing the volume at each feeding, and improving calorie intake. You can use your own pumped milk, fortified breast milk, or formula in the supplementer. This device works best for younger babies and may not be well accepted by babies older than four months who sometimes prefer breastfeeding without a tube attached to the breast.

### Establishing and maintaining an adequate milk supply

If your newborn baby is breastfeeding eight or more times per day, is draining the breast well at each feeding, and is getting enough milk from breastfeeding to gain weight, it is likely that your supply will be adequate. However, if your baby is in heart failure, or as your baby approaches surgery, he may have difficulty completing each breastfeeding and draining your breasts effectively. If this is the case for your baby, you will need to add pumping to your daily routine to maintain your supply. If your baby is able to continue to breastfeed, you can follow every breastfeeding attempt with a pumping session to completely empty your breasts and to assure that you maintain adequate milk production.

If your baby requires surgery in the newborn period, or is unable to nurse right away for some other reason, you will need to establish your milk supply, typically by pumping. It is essential to use a good quality double electric pump, and to pump at least 6-8 times every 24 hours. Be sure to pump at least once in the middle of the night between midnight and 7 a.m., not going more than 5 hours in between pumping sessions. Thorough emptying of your breasts every few hours

will maintain your supply and will ensure that you have enough milk when your baby is ready to return to nursing at the breast. If your baby is older than six months, you may be able to pump fewer times per day and have longer intervals between pumping, especially overnight (see pumping chapter for detailed information).

Monitor your supply carefully. The first few days after your baby's birth, there will be drops of colostrum that are vital for your baby's immune system. Don't waste these precious drops! You can swab the inside of your baby's mouth with this colostrum, which will be absorbed into his bloodstream to protect him from infection (see NICU chapter for more information on oral administration of colostrum). If you pump, your supply will gradually increase each day and by the time your baby is 7-10 days old, you should be producing 750-800 mL (25-27 ounces) per day. Continue to monitor your supply to be sure that you are producing enough milk for all of your baby's feedings. Using a notebook or smartphone app can help you keep track of your daily production. If you detect a decrease in supply, it can be corrected with more frequent pumping. Your breastfed baby's intake may be low due to challenges in his ability to feed before his surgery, and your supply may have adjusted to produce only the amount he is drinking. Pumping, in addition to breastfeeding, will help increase your milk supply. The goal of milk expression is for you to produce the amount that your baby would take if he were not in heart failure. It is important to establish a full milk supply from the beginning, as it's harder to increase your supply later if it has not been established in the early weeks. You can freeze any milk your baby is not using for later (see the appendix for information on proper storage of breast milk).

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**The goal of milk expression is for you to produce the amount that your baby would take if he were not in heart failure.**

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## HEART FAILURE AND INSUFFICIENT WEIGHT GAIN

*Heart failure* is a progressive condition in which the heart can't keep up with the demands on it. In heart failure, the heart muscle is working extra or, in the final stages, is unable to pump enough blood to meet the body's needs for blood and/or oxygen. Infants with AVSDs or large VSDs generally develop heart failure within a few weeks of birth. This is because an excessive amount of blood flows through the hole, or holes, sending too much blood to the lungs. The excess of blood causes the lungs to stiffen, in turn requiring infants to work harder and faster to breathe. This "increased work of breathing" as it is sometimes called, often means babies in heart

failure have issues with weight gain. There are several likely reasons for this: eating requires effort and stamina, and babies with some types of heart failure may tire faster compared to babies who are not in heart failure. Babies in heart failure often feel hungry and show great enthusiasm at the start of a feeding, but soon, because of the extra effort they need to put into feeding, they are sweating, tired, and have fallen asleep or lost interest. Therefore, babies in heart failure may abruptly end the feeding due to fatigue before they are full and before the breast is emptied. Another cause of poor weight gain is that babies with some types of CHD need more calories because their heart is working harder to pump blood throughout their body. These babies are burning more calories just managing their basic heart functions, and so there are fewer calories left for growth. Additionally, when heart failure progresses to a more severe form and reduces blood flow throughout the body, there may be limited absorption of nutrients from the intestines, resulting in poor weight gain.

## Monitoring your baby's growth

Your baby's weight will be carefully monitored because weight gain is closely linked to nutritional status. You and your child's medical team can discuss ways to improve your baby's growth and nutrition. If your breastfed baby is latching well and is able to maintain adequate suction to empty your breast at each feeding but still is not gaining weight, then he likely needs more calories. It is common for babies with CHD to work with a Registered Dietitian Nutritionist (RDN). Based on your baby's weight and estimated calorie needs, the RDN will give you a diet plan with goals for how much your baby needs to eat every day to grow and gain weight. Babies with CHD may have increased calorie needs because their heart needs to work harder, yet they tire easily and often don't get enough to eat.

If your baby is not gaining adequate weight, his medical team may want to know exactly how much he is drinking at each breastfeeding session. If you are mostly or exclusively feeding directly at the breast, you can use an electronic scale to weigh your baby before and after every breastfeeding to determine his intake. These are called pre- and post-weights and you can learn more about it in the newborn chapter. Since babies do not always drink the same amount at each feeding, it is important to measure the amount of milk your baby gets at every breastfeeding for 24 hours to determine his total daily intake. A scale used for this purpose should be accurate to within two grams and can often be rented from a medical supply company.

While your baby's health is the most important concern, you will probably also want to discuss your personal breastfeeding goals with your baby's medical provider. If your baby still can't gain weight despite efforts to increase his calorie intake, that may be an indication that it is time for his heart to be repaired. The stronger your baby is and the better his nutritional status at the time of surgery, the more likely he will have a good surgical outcome and spend less time recovering in the hospital.



## INCREASING CALORIE INTAKE IN THE BREASTFED BABY

If your baby does not meet his daily calorie goals at the breast, you can pump and provide extra milk in a bottle or supplemental nurser. Many mothers worry that introducing their breastfed baby to a bottle may cause their baby to reject the breast and prefer the bottle. However, we do not have enough evidence to know if this is true. It is likely different for every mother and baby. Studies in preterm infants in the Neonatal Intensive Care Unit (NICU) have not shown that bottle feeding while babies were learning to breastfeed reduced the rate of breastfeeding after discharge home. If supplementing your breastfed baby with a bottle of pumped milk to increase his intake does not improve weight gain, it may also be necessary to increase the calories of your milk.

If your baby is able to take in enough volume at each feeding, increasing the calories of the milk he is drinking may be helpful. Adding extra fat to each feeding is a good way to do this. This can be done either directly at the breast or with a bottle of expressed milk. Please note, the amount of fat in your breast milk can vary during a pumping session and at different times of the day. Also, some mothers naturally have higher fat milk. The amount of fat in your breast milk is not related to your own weight or to anything you are eating.

Your milk can be customized to increase the calories and fat you feed to your baby to help him grow. For most breastfeeding mothers, fat is naturally added to the milk as the baby breastfeeds. The first milk that comes out of your breast is called *foremilk*. As you continue to breastfeed or pump, more fat is added to your milk, and the fat content gradually increases. When your breasts are very full, there is less fat in the milk. When your breasts are less full, the milk is fattier. Foremilk contains protein and other nutrients, but it is lower in calories and fat. As the breast is emptied, the amount of fat in the milk gets higher, and the milk has more calories. The milk that flows after the foremilk is removed is called *hindmilk*. Massaging your breasts during breastfeeding will add extra fat and calories to your milk.

Other ways to increase the calories in your milk include:

- **If you are directly breastfeeding your baby**, you can express milk before each feeding to remove some of the foremilk. Foremilk appears more watery and thinner than hindmilk. When the milk consistency and the color change to darker, thicker milk, you can stop expressing and place your baby to your breast. The amount you need to remove may vary at different times of the day or at each breast. The goal is to initiate milk flow until you have a letdown and you see more fat in your milk. This process will also help your baby conserve energy because milk will flow as soon as he starts sucking. This method works best if you produce more milk each day than what your baby is drinking. You can save and freeze the foremilk for use later, when calories are not such a concern.

## Foremilk vs. Hindmilk

KIMBERLY H. BARBAS, BSN, RN, IBCLC

The fat content of breast milk changes naturally throughout the course of each feeding or pumping session. The first breast milk in the early part of a feeding that your baby will receive is lower in fat and calories, and is referred to as **foremilk**. Fat is actively added to your milk during a feeding or pumping session. The breast milk towards the end of a session is referred to as **hindmilk**.

Your milk will contain a mixture of foremilk (one-third) and hindmilk (two-thirds) but as your baby nurses, or as you pump, more of that higher fat milk is removed from your breast. This is why it is important to drain your breasts effectively, and make sure your baby finishes feeding on the first breast before switching to the second breast. Very short or strictly timed feedings may mean your baby will miss out on a balanced feeding and only receive the low-calorie foremilk.

Some mothers who are making more milk than their baby can drink at one feeding can use hindmilk to their advantage to help their baby gain weight. If your baby needs extra calories and you are pumping to bottle feed, you can separate your milk to provide your baby more of the higher fat milk. You will need to produce about one-third more volume than the amount your baby needs every day.

### How to separate foremilk and hindmilk:

1. Track your normal daily pumping volumes with a smartphone app or with a pen and paper log.
2. Determine one-third or 30% of your average pump volume. For example, if you normally pump 60 mL (2 oz) from each breast, one-third (30%) will be 20 mL ( $\frac{2}{3}$  oz). This is your estimated foremilk volume.
3. Pump to remove that first one-third volume, the foremilk, and then stop. Pour this into a separate container and label it **FOREMILK**. It can be frozen to use when your baby's weight is no longer a concern or to mix with solids later.

4. Continue pumping for the duration of your session. This is considered your hindmilk. Use this to feed your baby to help promote better weight gain.

If you are directly breastfeeding, you can also take advantage of hindmilk if you are producing more milk than your baby drinks at one time. Use your breast pump or hand express for several minutes **BEFORE** breastfeeding to remove some of your foremilk volume (steps 1 to 3 above) and then breastfeed your baby. This will increase the hindmilk intake (higher fat and calories) that your baby receives directly from the breast.

- **If your baby is drinking your pumped milk in a bottle**, you may be able to separate your milk while pumping to give him milk with higher fat content. You can increase the fat and calories in your milk by making some changes to the way you pump (see sidebar on foremilk and hindmilk). Research has shown that breast milk that is expressed by hand is higher in fat than milk that is expressed by an electric pump, so, to increase the fat in your baby's diet, consider hand expressing your milk for at least some pumping sessions or engage in hands-on pumping (see pumping chapter for more information).

You can also increase the fat and calories of your pumped milk by enriching it with the high-fat portion from another bottle of your breast milk. Begin by letting a bottle of your milk separate in the refrigerator over the course of a few days. (According to the Centers for Disease Control and Prevention, you can store freshly pumped breast milk in the refrigerator for up to four days. See appendix for further guidelines for breast milk storage). After a day or so, you will see the cream rise to the top of the breast milk in the container. Your own cream is high fat and easy for your baby to digest. Once the cream has risen to the top, you can use a small spoon to remove some of it to add to another bottle of your breast milk as you prepare to feed it to your baby. Gently swirl the bottle until the fat is fully incorporated into your milk.

Your healthcare provider may also talk with you about fortifying your milk. This is a very common strategy to improve weight gain in children with CHD. This method requires that you pump your milk to bottle feed to your baby. You will be given a recipe to mix a small amount of formula into your pumped milk to increase the calories your baby gets. If anyone in your family (yourself or your baby's father or his siblings) has food allergies, it's important to discuss this with his health care provider so they can choose an acceptable formula. Most babies tolerate fortification but if you notice any changes in your baby's behavior such as increased crying or gassiness, or changes in stooling patterns, or any other signs that he may not be tolerating the formula fortification, be sure to let his healthcare provider know so they can adjust it.

## Supplemental enteral nasogastric (NG) feedings

In the event that all of the above measures have been tried, pre- and post-weights, hindmilk, fortification, and your baby still cannot get enough calories to gain weight by oral feedings, his healthcare provider may suggest enteral feeds with a nasogastric (NG) tube. As heart failure worsens, it may be essential for your baby to conserve energy, and a simple way to do that is to limit the effort of feeding. Babies on oxygen can continue to feed orally as long as they are not exerting too much effort during feedings. Your baby's medical team may restrict his oral feeding, only allowing him to feed at the breast or bottle for a short time each day. Your baby may actually self-limit feedings or even refuse to feed orally due to the effort it takes. This can be extremely concerning for parents. You may feel discouraged and disappointed if your baby no longer wants



*Seraphina is receiving a gavage feeding through her NG tube while practicing her latch.*

to breastfeed, or will only breastfeed for a minute or two at each feeding. These feelings are normal. You may also be disappointed if your baby's medical team suggests an NG tube, but try to view using an NG tube as a positive strategy to improve the quality of any oral feeding experiences (see chapter on tube feeding for a list of questions to ask the medical team if tube feedings are being considered for your baby). With an NG tube, you know your baby is getting adequate nutrition, and so there is less pressure to assure he finishes his oral feeds, and any oral feedings can be used for comfort and can be enjoyed by you and your baby without worrying if he is getting enough calories to gain weight. You can hold your baby skin-to-skin during tube feeds to maintain physical closeness and bond. If allowed, and your baby is interested, you can offer an empty breast after you pump so he can continue to practice oral feeding skills. These non-nutritive sucking sessions can be comforting and relaxing to you and your baby.

## IF YOUR BABY NEEDS HEART SURGERY

Not all heart defects will require surgery. The timing of surgery also varies. However, if your baby does need surgery to repair his heart defect, there are some things you should know to help you be more prepared during this process. If your baby is scheduled for surgery, he will need to **fast** (be without food and drink for several hours before surgery). According to the American Society of Anesthesiologists and the Academy of Breastfeeding Medicine, a baby can have human milk up until four hours before surgery. Human milk is not a clear liquid (examples of clear liquids are water or apple juice), which can be given up to two hours before surgery, but human milk is easier to digest than formula. A formula-fed baby will need to fast six hours before having anesthesia for surgery. Someone other than you may need to comfort your baby during this fasting period because breastfed babies often are not happy being with their mothers if they cannot eat. If you are holding your baby or he hears your voice, he will likely expect you to breastfeed him. Consider having your baby's dad, grandparent, or another adult walk with him in a sling or carrier, or use a swing or other device that your baby normally finds soothing to help him get through the hours of fasting.

## Feeding after heart surgery

Families often assume that after the heart surgery, the baby will be stronger, and feeding will not require as much effort; however, after surgery, your baby may still have difficulties with feeding. In babies requiring surgery in the first month of life, there is an increased risk of feeding difficulties until two years of age. Food refusal and lack of appetite are common after surgery. Your baby's suck-swallow-breathe pattern may be uncoordinated, and he may lack the muscle strength to extract milk from the breast or bottle. This impaired coordination is common after heart surgery and is considered a risk factor for *dysphagia* (difficulties with swallowing). However, breastfeeding has been shown to be better than feeding from a bottle for babies who have had heart surgery. In a recent study of 31 infants 0-6 months old after cardiac surgery, it was found that bottle-feeding resulted in more difficulties with the suck-swallow-breathe pattern that is required for safe and successful feeding. Babies had more trouble staying attached to a bottle nipple than the breast, and bottle-fed babies had more coughing and choking episodes during feeding than breastfed babies.

You may be eager to resume breastfeeding as quickly as possible after your baby's surgery, but you will most likely need to be patient as your baby's interest in feeding and appetite slowly increase. Your baby may not be interested or able to feed at first and may still require NG feeds, or he may have pain or be uncomfortable in certain positions. Ask your baby's nurse or your IBCLC to help

### Pro Tip



In a recent study of 31 infants 0-6 months old after cardiac surgery, it was found that bottle feeding resulted in more difficulties with the suck-swallow-breathe pattern, which is critical for safe and successful feeding. The babies in the study had more trouble staying attached to a bottle nipple than the breast, and bottle-fed babies had more coughing and choking episodes during feeding than breastfed babies.

you find a position for feeding that is comfortable for both you and your baby. Since bottle feeding is more passive, your baby might prefer to bottle feed after his surgery. If the medical team wants to monitor your baby's fluid intake after surgery, or he can't be moved easily out of bed to breastfeed, you can pump and bottle feed him until you can breastfeed him. When your baby is ready, help him prepare to return to the breast by holding him skin-to-skin and gently offering your breast when he is drowsy and calm. This can be a relaxing and peaceful time for both of you. If your baby is very hungry, he may not have the patience to try to breastfeed, so consider feeding him some milk from a bottle first and then offer the breast.

Continue to offer the breast often throughout the day and night if you are able to sleep in the same room with your baby. Do not get discouraged if breastfeeding

does not improve immediately. This is a process, and the progress you and your baby make may take place over many days or weeks. Even after you are home with your baby, you may continue to worry about his feeding and weight gain. If you feel this way, know that you are not alone. Feeding problems can be a significant source of stress for many families after major cardiac surgery. Be sure to reach out for help from care providers who are supportive of breastfeeding. Feeding programs that include a speech-language pathologist can help you and your baby relearn feeding skills. As your baby's endurance and interest in feeding improve, you will see progress in his ability to breastfeed. Reaching out to an IBCLC who has experience in helping mothers and babies with special needs can also help improve your baby's breastfeeding skills. Be patient!

With time and support, you and your baby will be successful in reaching your breastfeeding goals.

## Benefits of Breastfeeding During Hospitalizations

HEATHER MILLER

Many babies with Down syndrome will be hospitalized at some point in their first few years of life due to heart problems, breathing issues, or other medical complications or illnesses. During these hospitalizations, many mothers are grateful for their breastfeeding relationship with their child. Benefits of breastfeeding your child during a hospitalization include:

- Breast milk can boost your baby's immune system and help him to heal more quickly from illnesses or surgeries.
- Being hospitalized can be confusing and disorienting for any child. Being away from the routines and comforts of home, seeing many new faces, and undergoing medical procedures may be distressing. Breastfeeding can comfort your child during these difficult times.
- According to the American Society of Anesthesiologists and the Academy of Breastfeeding Medicine, a baby can have human milk up until four hours before surgery versus formula, which can only be given until six hours before surgery.
- Check with your child's medical team regarding the hospital's policy on breastfeeding and general anesthesia.
- Patients are often required to tolerate food or fluids before being discharged from the recovery room. Breastfeeding may be easier for your child to manage than other types of foods or fluids.
- Breastfeeding just before or during a test or invasive procedure can keep your baby calm and distracted. This familiar ritual can also help your baby feel safer and can make it easier for the healthcare professional performing the testing.

## Chylothorax After Cardiac Surgery

KIMBERLY BARBAS, BSN, RN, IBCLC • RACHELLE LESSEN, MS, RD, IBCLC, LDN

**Chylothorax**, the accumulation of lymphatic fluid in the **pleural** space (around the lungs), is a complication occurring in 3-9% of children following congenital heart surgery. It is most often caused by direct injury to the thoracic duct during surgery. The lymphatic system drains excess fluid within the body and transports it back into the bloodstream through the lymphatic vessels. One of these vessels is the thoracic duct. The fluid carried within the lymphatic system is called **chyle**. It has a milky-white appearance and contains fats, protein, and immune cells. When there is an injury to the thoracic duct, this fluid can leak and accumulate in the spaces around the lungs instead of draining directly into the bloodstream. This loss of nutrients and immune cells increases the risk of malnutrition, impairs the immune system, and may lead to breathing problems due to the fluid around the lungs.

Chylothorax usually appears about 24-48 hours after breast milk is fed to the infant following surgery. When a baby has this complication, doctors will notice that chyle fluid is draining out of the chest tubes, which are routinely placed during heart surgery. This fluid is constantly monitored, and chyle is usually quickly identified. To decrease the production of this fluid, your baby must not have fats, specifically long-chain triglycerides.

Unfortunately, the fat in breast milk is mostly the long-chain variety. The treatment for this condition is usually a low-fat formula that is made from medium-chain triglycerides (MCT) such as Enfaport® or Monogen®, or breast milk that has had the fats removed by skimming the milk after it is processed in a centrifuge. Not all hospitals can provide this service, so ask your lactation consultant if it is possible. This skimmed breast milk is then fortified with MCT formula and, if needed, with MCT oil as well, to provide the calories your baby needs. This allows your baby to continue to receive the benefits of breast milk while he recovers. This low-fat diet is usually given for four to six weeks to allow the leak to heal.

The process of skimming the breast milk removes about 20% of the volume. If you have a low milk supply, you might decide to use the MCT formula during the treatment instead of breast milk, and save your pumped breast milk for later. It is important to keep pumping your breast milk to keep up your supply until your baby can breastfeed or have your breast milk again (see pumping chapter for more information). If your baby must continue the low-fat diet after he comes home from the hospital, it may not be possible to continue with skimmed breast milk, and you may have to switch to MCT formula to complete the treatment.

A creative approach to skimming breast milk that worked for one family was to use the spin cycle on a washing machine. Syringes containing expressed milk were capped, secured to the washing machine agitator, and spun for 20 minutes. The fat was successfully separated, and the mother was able to fortify this milk and feed it to her baby.

Some families have separated the fat from a bottle of breast milk by letting it sit in the refrigerator so that the fat rises to the top. This method is useful for skimming milk for infants with chylothorax when a refrigerated centrifuge is not available. It can be done in both the hospital and home setting. Milk should be freshly expressed and will need to sit undisturbed in the refrigerator for up to four days. The final skimmed milk and separated cream can be frozen for later use. Some milk may not adequately separate and will not be suitable for use for this purpose, but may still be frozen for later use after your baby has recovered from chylothorax.

There is limited research to show that these methods are effective, so speak to a lactation consultant at your hospital for instructions and more information. Practice these methods before you are discharged home, and be sure to discuss the risks with your child's cardiologist.

## Skimming Milk Without a Centrifuge

- Start with freshly pumped milk.
- Insert a 60 mL syringe into the container of milk and draw milk up into the syringe. You can buy these from a medical supply company or get them from the hospital before you go home.
- Put a cap on the end of the syringe.
- Place the syringe into the now empty milk container with the tip down and plunger up.
- Put it in the refrigerator in a spot where it will not be disturbed.
- After a few days, you will see a layer of cream on the top and skimmed milk on the bottom. Use a new, clean container to collect the skimmed milk. Remove the cap, and push down on the plunger to release the skimmed milk from the bottom of the syringe. Stop before you get to the cream layer.





## Overview of Breastfeeding Challenges and Interventions for Babies with a CHD

Challenge	Intervention
<b>Poor latch</b>	<ul style="list-style-type: none"> <li>• Seek help from an IBCLC.</li> <li>• Consider using a nipple shield.</li> </ul>
<b>Tired with feeds, resulting in short feeds</b>	<ul style="list-style-type: none"> <li>• Offer short, frequent feedings.</li> <li>• Consider dancer hand position.</li> </ul>
<b>Breast refusal</b>	<ul style="list-style-type: none"> <li>• Practice skin-to-skin contact.</li> <li>• Offer breast at least once daily when your baby is calm.</li> </ul>
<b>Poor weight gain</b>	<ul style="list-style-type: none"> <li>• Measure milk transfer with pre- and post-weights.</li> <li>• Offer supplemental feedings with a supplemental nurser or bottle.</li> <li>• Separate hindmilk to provide more fat and calories.</li> <li>• Consider hand expression or breast massage to increase the fat in your milk.</li> <li>• Fortify with formula to increase calories.</li> </ul>
<b>Inadequate milk transfer</b>	<ul style="list-style-type: none"> <li>• Seek assessment from a feeding specialist or an IBCLC.</li> <li>• Increase the number of feedings per day.</li> <li>• Supplement with a supplemental nurser at the breast or with a bottle.</li> <li>• Discuss a feeding tube with your child's medical team.</li> </ul>

## Mom Story

### JANA & KENDON



My son, Kendon, was born at full term with a birth diagnosis of Down syndrome and a complete AV canal defect. He breastfed right after he was born and continued with diminishing success until about 11 days old when we couldn't wake him to feed. His heart failure made nursing hard work for him, and he received an NG tube in the hospital a few days later. I was devastated that I couldn't nurse him anymore, and I sobbed while talking to the lactation consultant at the hospital. I felt like everything was being taken away from me. First, he had Down syndrome, a heart condition, and a thousand appointments, then he couldn't breastfeed—it tired him out too much and took too much energy. We relied on pumping and bottle/NG feeds. I tried to put him to the breast once a day at the recommendation of my lactation consultant who assured me that sometimes babies did resume breastfeed-

ing after a long hiatus. I was dubious, and he rarely latched, but I was willing to do just about anything to get my baby to breastfeed again.

One of the amazing parts of Kendon's story was that even though he initially didn't gain weight as fast as the doctors wanted him to, we were able to manage his feeds completely with my breast milk. I had two fantastic lactation consultants who worked with his cardiologist to tweak my milk; I wish more doctors and moms knew about what you can do with breast milk! I pumped off the foremilk and froze it for a donation to a milk bank. Then I pumped the fatter hindmilk into a separate container. We left some of this hindmilk to separate overnight in the refrigerator and then skimmed off the fat that rose to the top. We added that fat to my regular hindmilk to make a milkshake of sorts. We also gave Kendon 1mL MCT oil along with the milkshake, so that he could use the oil for energy and store the fat from my breast milk. It was crazy trying to keep all that milk straight in my fridge! The staff at the hospital that admitted him were baffled by what we affectionately termed milk chemistry (my husband is a chemist).

The other amazing thing about Kendon's story is that he eventually resumed breastfeeding! He had his heart repair when he was 10 weeks old. Just before he turned 5 months old, he resumed breastfeeding exclusively and never looked back. I was so done with the pump and the bottles and the NG tube. He breastfed until about 14 months old, when we switched to straw cups. I didn't know it was possible, but with the help of my lactation consultants, we did it! My son is now 3 years old, and he is doing really well!

## Mom Story

### MERCEDES & MILA



Mila is a blessing to our family; she is our first daughter and the first granddaughter in the family. We are lucky to have such a wonderful little girl who is strong, determined, and above all, very lovable. She was born with Down syndrome and diagnosed with a congenital heart condition known as complete atrioventricular canal defect. Both diagnoses were a complete surprise, and it was very difficult for us to make sense of it all at the beginning. The first words we heard from the doctors at the hospital were, "Sorry, we have bad news." We immediately thought her life was in danger. Soon after, we heard the words "Down syndrome" and we began the emotional roller coaster ride of doubt, despair, and acceptance. We honestly didn't know what to think at first; we were expecting

to hear "Congratulations! Your baby girl is healthy and doing well." Her pediatrician detected her heart defect a few days after she was discharged from the hospital, which put Down syndrome temporarily on the back burner. Although the first few weeks were full of emotional turmoil, we continued our breastfeeding journey as we had always intended to do.

Breastfeeding didn't come naturally for Mila. We had to work with nurses, lactation consultants, and Mila's pediatrician to better understand why breastfeeding wasn't going well. Unfortunately, Mila was not gaining weight, and we noticed that she struggled after breastfeeding, even if the session was only a minute or two long. She would take deep long breaths after feeding, would sweat profusely, and sometimes her lips would turn purplish, and she would be very tired. Her heart defect was a huge factor in her lack of progress. We decided to supplement my breast milk to ensure that she was receiving enough calories to gain weight before her heart surgery. From that point on it was easy to rely on formula to make up the lack of calories from breastfeeding. I never thought to pump after every feed to keep my supply up. I guess I never thought she could recover fully and get back to breastfeeding exclusively. That option was never presented to me, and so I kept doing what I was told: Breastfeed her as much as she could tolerate, supplement after breastfeeding, and pump once a day to have some supply for when I would go back to work.

Mila had her heart surgery when she was three months old, and it was a great success. She finally could breastfeed for minutes at a time without becoming overtaxed. The stress of breastfeeding was gone, but so was my supply. I kept breastfeeding and supplementing for another five months, but soon there was nothing left to give. I always question whether or not things would have gone differently if I had pumped more. I've had to keep reminding myself that I tried everything I could at the time. Despite the challenges, we prevailed and I'm proud of the two of us for sticking to breastfeeding for eight long months. It was a great learning experience and an opportunity for us to bond. This was one of the many challenges we have been able to overcome. Mila has been a fighter since the day she was born, and she continues to change the way we think about Down syndrome.

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*Freya practicing her breastfeeding skills before weaning from tube feeds*



## Feeding Tubes

KATHLEEN CARR, DNP, RN, CPNP

There are various reasons that your baby may require a feeding tube. For example, babies with Down syndrome (DS) are more likely to be born prematurely, and premature babies sometimes have difficulty with their suck-swallow-breathe coordination, which is critical for oral feeding. There may be other reasons that your baby's medical team has suggested a tube for your baby's nutrition. The good news is that you should still be able to express your breast milk to give to your baby through her tube. Pumping to initiate and maintain your supply will be critical while your baby is tube fed, particularly if your ultimate goal is to get your baby to direct nursing at the breast. It may help to know that research shows that preterm babies who are tube fed often have a higher rate of eventually making it to the breast versus those who are bottle fed. It is important to let your baby's medical team know your feeding preferences for your child from the start.

## WHY WOULD MY BABY NEED A FEEDING TUBE?

Pediatric feeding tubes, also called enteral tubes, are used to provide some or all of the nutrition that an infant or child needs. Your baby may need a feeding tube if she has been born prematurely (before her suck-swallow-breathe coordination is fully developed), is not growing and gaining weight properly, or if she has swallowing difficulties that prevent her from being able to take in the foods and fluids orally that she needs to grow and thrive. Sometimes a baby may be able to take part of her nutrition by mouth, but poor coordination with feedings, fatigue, or prematurity may mean she is not able to take in enough by mouth to meet her nutritional needs. When this

happens, your baby may only receive a portion of her nutrition via a feeding tube. In this case, your baby may be able to breastfeed for some of her feedings, while receiving the remainder of her calories through her feeding tube. Discuss this possibility with your child's medical team. If your baby is very premature, has poor coordination, or aspirates when feeding orally, she may need to receive all of her nutrition via a feeding tube. For most babies, oral feeding is the ultimate goal, and a feeding tube is used only as a bridge to help support them until they can take all of their feedings by mouth. Except in very special circumstances, breast milk can be given via an enteral tube. In some cases, for example, if your baby is not gaining weight quickly enough, a combination of breast milk with some formula powder may be suggested to meet your child's calorie needs. Your baby's gastroenterologist may consider allowing you to increase the calories your baby is receiving by using your own breast milk. Speak with your baby's medical team or your IBCLC about this possibility. If this is something your baby's medical team agrees to, see the sidebar in the heart chapter for more information.



### Mom Tip

Pumping is the key to ensuring that your milk supply is robust enough to meet the needs of your baby when she is ready to feed orally. It is important to pump as often as you would breastfeed your child, typically every few hours, in order to maintain your supply. The amount of milk you are able to pump at each sitting may vary depending on a number of factors including the time of day, the last time you were able to pump, your stress level, and your overall milk supply. It is important for you as a lactating mother to pay particular attention to your own nutrition and hydration needs in order to maintain your supply. After pumping, your milk can be given to your baby or refrigerated or frozen for later use.

## HOW WILL I DECIDE IF A FEEDING TUBE IS RIGHT FOR MY BABY?

Your baby's pediatric gastroenterologists or nurse practitioners, working with other specialists such as dietitians or nutritionists, speech-language pathologists, lactation consultants, or occupational therapists, will determine whether your baby needs a feeding tube. Once a feeding tube is recommended, the team will work with you and your family to decide how and when the feeding tube will be used, if oral or breastfeeding is safe to continue, and when and what to feed your child to ensure adequate growth. When necessary, medications can also be given via a feeding tube if your child is unable to take them by mouth.

The process of figuring out the safest and best way to feed your child may be very stressful. You may feel that your desire to breastfeed has taken a backseat, or that it may not be possible at all. However, this need not be the case. It is important that you communicate closely with your child's medical team to understand why a feeding tube is recommended and what the expected plan for feeding will be once the tube is placed. Let your baby's medical team know that your ultimate goal is to breastfeed your baby and ask for this goal to be included in the plan to transition your baby to oral feedings. Ask your child's medical team how long the tube will be needed, and what the plan is for transitioning to full oral feeding. Communicate regularly with your child's medical team to troubleshoot any problems, ask questions, or modify the feeding plan, as needed.

If you have objections to a feeding tube, it is important that you discuss these concerns with your child's medical team before the tube is placed. While many families are reluctant to use a feeding tube initially, they often feel less stressed once the tube is placed, knowing that their child is receiving the nutrition she needs to thrive and grow.

### Questions to Ask Before Tube Placement

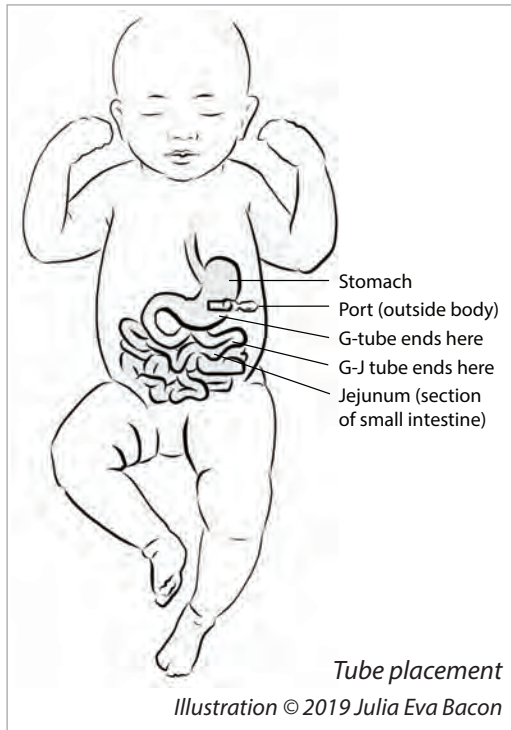
Consider asking your baby's medical team the following questions to help you weigh whether a feeding tube is right for your baby.

- Why does my child need a feeding tube?
- Will my child still be able to eat by mouth? If so, how much and how often?
- How long will my child need a feeding tube?
- What type of feeding tube does my child need (i.e., nasogastric, gastrostomy, gastro-jejunal)?
- What will my child be fed via the feeding tube and when will she be fed (daytime/nighttime)?
- Will my child's activities be limited in any way?
- What is needed to care for the tube and who will provide this care? What equipment do we need and how do we get it?
- Can my child still go to school/daycare?



## TYPES OF FEEDING TUBES

The decision about which kind of feeding tube is recommended for your child will depend in part on how long it is anticipated your child will require the assistance of a feeding tube, as well as which route is thought to be the safest way to feed your baby. There are a few different types of tubes depending on where on the body where they are placed. You should discuss the best type of tube for your baby with your medical team.



A **nasogastric tube** (NG tube) is inserted in the child's nose and extends to her stomach. These tubes can be placed in a doctor's office, a hospital, or an emergency room. Typically, no special medication other than a water-based lubricant is needed when placing a nasogastric tube and placement is not considered a surgical procedure. Once placed, part of the tube will extend outside of the nose and will be secured to your child's cheek with special tape. The tube is then checked before using to make sure it is in the correct place, usually by testing its pH (a measure of acidity) with a special paper. In some cases, your child's medical team may request an x-ray to ensure that the tube is in the correct place. Depending on where your child is cared for, you may be taught how to insert the NG tube before your child goes home from the hospital. Please speak with your baby's medical team about who will be responsible for placing the tube should it fall out. It is important to be aware

that most medical facilities will have some feeding tube supplies on hand if your child needs to have her tube replaced; however, they may not have the same ones that you use at home. In some cases, a medical facility may not have the smaller tubes that an infant or child requires. Therefore, it is important that you keep extra tubes and supplies at home and bring them with you to the hospital or clinic if your child's tube needs to be replaced.

A **nasojejunal tube** (NJ tube) is similar to a nasogastric tube. In fact, it will look almost identical to an NG tube when it is taped to your child's cheek. The NJ tube is inserted through the nose just like an NG tube. However, it passes through the stomach and into the jejunum, which is part of the small intestine. An NJ tube is more difficult to place and requires the help of a

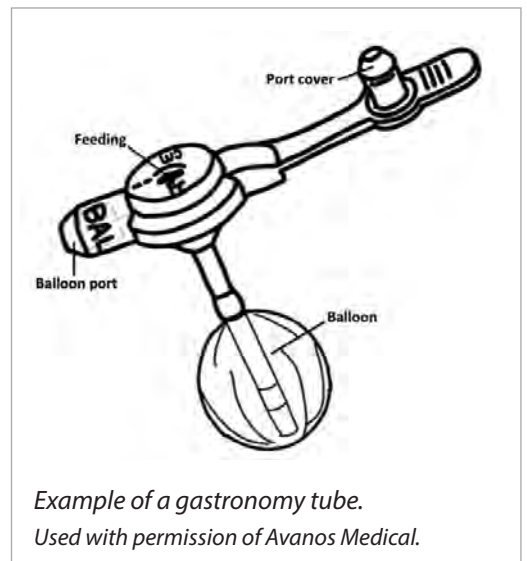
radiologist using a special type of x-ray called fluoroscopy. A small amount of dye is put in the tube during the x-ray to help doctors make certain the tube is in the correct place. An NJ tube is often used when a child is having a lot of vomiting when feeds are given into their stomach, if their stomach is slow to empty food, or if they aspirate their stomach contents into their lungs.

A **gastrostomy tube** (G-tube) is a feeding tube placed in the stomach through an opening known as a **stoma**. A stoma is created by making a surgical incision into the abdomen. This type of tube is placed while a child is under anesthesia, typically in an operating room or a special procedure unit within a hospital. There are different kinds of gastrostomy tubes, but they all have a disk, or **button**, that sits outside the body, on the abdomen, and a balloon filled with water that sits inside the body. This balloon helps anchor the tube and holds it in place in the stomach. Special tubing is then connected to a port on this disk and is used to give both nutrition and medication directly into the stomach. The port can also be used to help air escape from the stomach, called **venting**. Gastrostomy tubes can be changed at home by trained parents, by a visiting nurse, or in the clinic. They are usually replaced every 3-6 months.

Although placing a gastrostomy tube is a surgical procedure, removal of the tube when a child no longer needs it is a simple process. When a child is able to feed completely by mouth, the water is simply withdrawn from the balloon, and the button is gently pulled out. The stoma opening is covered with a dressing and will start to close within a few hours. The stoma should completely close within a few days to weeks. Until the **tract**,



*Kendon being fed at home through his NG tube.*

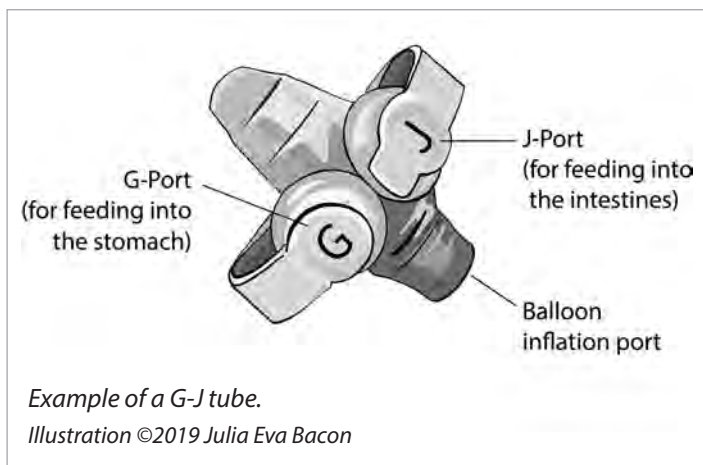


*Example of a gastrostomy tube.  
Used with permission of Avanos Medical.*

or opening in the stomach has closed completely, there will be some drainage of stomach contents. This is expected and the dressing should be changed as needed. In rare instances, if the tract has not closed completely within a few months, your child will be referred to a surgeon to have the tract closed in the operating room.

A **gastro-jejunal tube** (G-J tube) is similar to a gastrostomy tube and is also placed surgically. As with the G-tube, there is one disk that sits outside of the body on the abdomen, and a balloon that holds the tube in place in the stomach. However, a G-J tube has multiple ports on the disk that sits outside of the body, on the abdomen, and two different openings along the tubing on the inside of the body. One of these openings goes directly into the stomach and the second opening extends into the *jejunum*, which is part of the small intestine. Typically, children will be given continuous feedings through the jejunal (J) port, while the gastrostomy (G) port is used for medications or to allow air to escape from the stomach, as needed. Gastro-jejunal tubes

cannot be changed at home or in the clinic. Changes require a type of x-ray called fluoroscopy and are done by an interventional radiologist in the hospital approximately every three months. Similar to an NJ tube, a G-J tube is used when a child has trouble tolerating feeds that are given directly into the stomach, has persistent vomiting, or if there is concern for aspiration of stomach contents into the lungs.



## DETERMINING WHICH FEEDING TUBE IS BEST

Each type of feeding tube has its own advantages and disadvantages. The decision about which tube is right for your child depends on how long your child is expected to use the tube, if dislodgement is a concern, if there other issues to consider such as vomiting or aspiration, and childcare arrangements (for example, considerations for what type of tube a daycare will accept). Parental preference is always a consideration in the decision-making process, and you should feel comfortable speaking with your medical team about which tube may work best for your family.

## Feeding Tube Basics

Types of Tubes	Placement	Change Frequency	Advantages	Disadvantages
<b>Nasogastric (NG)</b>	In clinic	Every 4-6 weeks	<ul style="list-style-type: none"> <li>• Does not require surgical replacement. Can be placed in a doctor's office, a hospital, or an emergency room.</li> <li>• Typically short term use, 3-6 months.</li> <li>• Can be quickly placed to meet nutritional needs.</li> <li>• Continuous or bolus feeds are an option.</li> <li>• Can be changed by trained parents or caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>• Frequent accidental dislodgement and need for replacement.</li> <li>• Can be more difficult to place.</li> <li>• Taped to the face, making it visible.</li> <li>• Increased nasal congestion for some patients (resolves after tube removal).</li> </ul>
<b>Nasojejunal (NJ)</b>	Interventional radiology with fluoroscopic x-ray	Every 4-6 weeks	<ul style="list-style-type: none"> <li>• Good for patients with stomach motility issues, vomiting, or concern for aspiration.</li> <li>• Less risk of dislodgement than for NG tube.</li> <li>• Typically short term use, 3-6 months.</li> </ul>	<ul style="list-style-type: none"> <li>• Frequent accidental dislodgement and need for replacement.</li> <li>• Difficult to place, must be done in interventional radiology with a fluoroscopic x-ray.</li> <li>• Taped to the face, making it visible.</li> <li>• Increased nasal congestion for some patients (resolves after tube removal).</li> <li>• Requires continuous feeds approximately 8-24 hours/day.</li> </ul>
<b>Gastrostomy (G)</b>	Surgical	Every 3-4 months	<ul style="list-style-type: none"> <li>• Can be changed in the clinic setting or by trained parents/caregivers at home.</li> <li>• Easy to replace.</li> <li>• Less risk of dislodgement than for NG or NJ tube.</li> <li>• Continuous or bolus feeds.</li> <li>• Hidden by a shirt, so not readily seen by others.</li> </ul>	<ul style="list-style-type: none"> <li>• Surgical placement and anesthesia.</li> <li>• Granulation tissue develops and requires treatment.</li> <li>• Possibility of infection</li> </ul>
<b>Gastro-jejunal (G-J)</b>	Surgical	Every 3-4 months, by a radiologist using a fluoroscopic x-ray	<ul style="list-style-type: none"> <li>• Good for patients with stomach motility issues, vomiting, or concern for aspiration.</li> <li>• Feeds are given continuously through the jejunal port, with medications given as needed through the gastrostomy port.</li> <li>• Less risk of dislodgement than for NG or NJ tube.</li> <li>• When ready to start gastrostomy feeds but unsure if tolerated, the jejunal port can be used as backup.</li> <li>• Hidden by a shirt, so not readily seen by others.</li> </ul>	<ul style="list-style-type: none"> <li>• More likely to clog than a G-tube.</li> <li>• Must be replaced in interventional radiology with fluoroscopic x-ray.</li> <li>• If using jejunal port for feedings, they must be continuous.</li> </ul>

## PREPARING TO BREASTFEED

If your ultimate goal is to get your baby to feed directly at the breast, then there are many ways that you can prepare your body and your baby that will help with this transition even while your baby is receiving nutrition through a tube. For example, practicing skin-to-skin contact during this time will be extremely helpful in developing your breast milk supply. Make sure to mention your desire to practice frequent skin-to-skin contact with your baby's medical team, and ask them how to do this safely with your baby. You can also request that your baby receive tube feeds while you are holding her skin-to-skin in order to help her associate feeding and feeling full with you.

In addition to practicing skin-to-skin contact, you can also allow your baby to engage in non-nutritive sucking (NNS) by licking or nuzzling a pacifier or your finger. Remember that anything placed in your baby's mouth should be sterile or freshly washed. Your baby can also use your breast for NNS. It is recommended that you pump to fully empty your breasts before bringing your baby to breast to practice NNS to ensure that she does not aspirate. Your baby can engage in NNS when she needs soothing, or while receiving tube feeding, in order for her to begin associating suckling with feeling full and content. It is important to keep all oral stimulation interactions positive, and never to force a baby to take a nipple or pacifier into her mouth when she is uninterested or not ready. Depending on how old your baby is, she may show signs of stress with oral stimulation by crying, refusing to open her mouth, or turning her head away. If your baby is showing signs of stress with oral stimulation, it is okay to give her a break and try again another time. It may take multiple tries to get your baby to accept a nipple or pacifier but don't get discouraged!

## TRANSITIONING TO THE BREAST

As your baby grows and becomes stronger, her oral feedings will likely become more coordinated and efficient. If your baby's medical team agrees, now could be a good time to trial oral feedings. Her tube feedings will continue to provide calories while allowing her to practice her skills at the breast. Before you begin, discuss with her medical team how long you should allow your baby to practice at the breast. They may suggest you start with just a few minutes a couple of times a day. For the best chance of success, start with short practice sessions just before your baby is due for her tube feeding, when she is just showing signs of feeling hungry but is not so hungry that she will be distracted while trying to nurse (see newborn chapter to learn how to identify early feeding cues). For example, if your child's medical team approves, you can spend 5-10 minutes offering your breast and allowing her to practice latching. If your baby shows signs of being tired or stressed, for example, if she is breathing too fast, or is showing other avoidance behaviors like turning her head away or pursing her lips, then take this as a sign to stop the session. If your baby

## Non-Nutritive Sucking

KATIE DAVIDSON, MS, CCC-SLP, BCS-S • KAYLA HERNANDEZ, MS, CCC-SLP, BCS-S

Babies have two different types of sucking. **Nutritive sucking** occurs when babies are swallowing milk and receiving nutrition from their sucking efforts. In contrast, during **non-nutritive sucking**, no milk is swallowed. The speed of nutritive versus non-nutritive sucking is different. With nutritive sucking, a baby typically sucks and swallows once per second. With non-nutritive sucking, the baby sucks more rapidly and with smaller jaw movements.

Non-nutritive sucking also happens during a normal breastfeeding session, typically at the beginning of feeding before the letdown (or milk-ejection reflex) occurs, or at the end of feeding when the breast is empty. It can sometimes be difficult to tell if your baby is actually swallowing milk while breastfeeding. Pre- and post-feed weights may be helpful in determining how much milk your baby is drinking while breastfeeding. If your baby is not growing well or still seems hungry after nursing, a consultation with a lactation consultant or feeding specialist can help you make sure that your baby is getting enough milk.

Over time, daily periods of non-nutritive sucking can help develop your baby's breastfeeding skills, endurance, and coordinated movements of the tongue, jaw, and lips. In addition, non-nutritive sucking on a parent's clean finger, their own hands, or a pacifier are common ways for babies to soothe themselves. If your baby gets overstimulated or distracted during attempts to breastfeed, you can hold her in a feeding position and offer non-nutritive sucking on your finger or

a pacifier. Once your baby is settled and focused after this non-nutritive sucking warm-up, she may be more successful in latching at the breast.

Non-nutritive sucking is particularly good for babies who are unable to eat by mouth due to prematurity, medical conditions, or significant feeding difficulties. You or another caregiver can help your baby to engage in non-nutritive sucking while she is receiving a tube feeding, which can help develop an association between sucking and the feeling of being fed, or satiation. For some babies, small tastes of breast milk can be given at the time of non-nutritive sucking by extending a clean finger or pacifier dipped in breast milk or by allowing the baby to latch to a fully pumped breast. Non-nutritive sucking can also help with digestion if a baby sucks on a pacifier during or after tube feedings. Non-nutritive sucking during tube feeding may also help milk empty from the stomach faster, which may decrease reflux.

While non-nutritive sucking is helpful in early infancy for sucking development and self-soothing, children over 2 years old should not use a pacifier or suck on their fingers, as this can cause problems with their teeth (**malocclusions**).

Overall, non-nutritive sucking can be an important way to allow your baby to learn to self-soothe, gain oral stimulation, and develop necessary oral-motor skills. Given these benefits, babies with Down syndrome should engage in non-nutritive sucking as a daily developmental activity.

is showing you these cues, try not to become discouraged. It is normal to have a few good feeding sessions and a few bad ones each day. As with anything, breastfeeding is a skill and it may take your baby a little longer to master it. As she gets stronger she will have more successful attempts and you should be able to transition to full oral feedings at the breast.

As your baby's stamina increases, her latch becomes stronger, and you start to see her swallowing some milk at the breast, test weights can be used to monitor intake. The volume your baby is able to take in at the breast can be subtracted from the amount provided by the next tube feeding. Once your baby is taking 50–75% of the total amount of breast milk she needs at each feeding from the breast, talk to her healthcare provider about a tube holiday or oral challenge. This means taking 24 hours and exclusively breastfeeding with test weights, or bottle or breastfeeding combined, to see if your baby can meet the desired goal oral intake without the tube. In this way, your baby can gradually wean from her tube feedings to taking all of her nutrition by mouth.

## **WEANING FROM TUBE FEEDS**

As your baby is able to take more by mouth, she will rely less on her feeding tube. As this happens, her medical team will talk with you and your family about weaning your baby off of her tube feeds. Weaning is the process whereby a child transitions from one feeding method to another. In many cases, you will be asked to give less breast milk or formula via the tube, with the goal of making your baby hungrier, increasing the likelihood that she will take her feedings by mouth. The tube weaning process is individualized based on your baby's progress. Your medical team will follow your baby very closely during this process to make certain your baby is able to meet her feeding goals and maintain a safe weight.

Hearing that your baby may need a feeding tube can be a scary and uncertain time for any parent, but especially for those with a desire to breastfeed. However, just because your baby needs a feeding tube does not mean that all hope for having a breastfeeding relationship with your child is gone. With a thoughtful team approach, you may be able to transition your baby to the breast over time while providing your expressed breast milk to her through her tube. This will allow her to receive the nutrition that she needs to grow and thrive, while gaining the skills that she needs to successfully breastfeed.

## Signs Your Baby May Be Aspirating

Aspiration is an infrequent but concerning complication. Babies with Down syndrome may be at a higher risk of aspiration due to low tone. If your baby is aspirating, you should discontinue oral feeds and speak with your baby's medical team before proceeding. Look for the following signs during feedings, which can indicate your baby may be aspirating:

- splayed fingers
- coughing, choking, or gagging
- watery eyes
- raised eyebrows

## Oral Aversion

KATIE DAVIDSON, MS, CCC-SLP, BCS-S • KAYLA HERNANDEZ, MS, CCC-SLP, BCS-S

Oral aversions can be stressful for both you and your baby. If your baby has an oral aversion, she may avoid or become upset with anything touching her face or mouth. Sometimes an oral aversion is severe enough to require tube feedings. Some babies will still eat by mouth but are visibly uncomfortable while doing so. Babies who are aversive often refuse to latch to the breast and can become distressed by breastfeeding attempts.

Oral aversion can develop for many reasons, including difficulty swallowing or underlying gastrointestinal discomfort, such as reflux or milk protein allergy. Babies who have experienced a lengthy NICU stay with many medical interventions (such as prolonged intubation, frequent suctioning, and medication delivery) may also be at higher risk for oral aversion. While these procedures are necessary, they can be stressful for the baby. Such experiences can cause babies to become fearful of any oral touch, even when it is intended to be positive. It is important to work with your baby's medical team to determine why she is orally aversive, as it can be difficult to overcome if she continues to experience discomfort.

Although overcoming oral aversion can be challenging, there are things you can do to help your baby through this process. First, minimize any unnecessary unpleasant oral experiences such as forceful feeding or tricking your baby to eat. You can then begin to create happier oral experiences, including gentle stroking, nuzzling, or kissing your baby's face. If your baby allows it, you can offer a pacifier or finger to suck. Older babies can be given toys or teething rings to bring to their mouths for exploration.

It is essential to follow your baby's lead throughout this process. Persistent attempts to feed or to touch her mouth or face, even if well intentioned, can cause her to become even more defensive or aversive. Give your baby a break if she shows you that she is overwhelmed. Some signs that your baby is distressed are turning away, fussing, or closing her eyes to disengage. If you are responsive to your baby's cues, she will learn that feeding and touching her face are safe activities. A feeding therapist or lactation consultant often can help you establish a healthy and satisfying breastfeeding relationship even if your baby has had an oral aversion. Your baby's pediatrician or your local Down syndrome group can help you identify a specialist in your area.



## Mom Story

### KELLI & KIANA



We first learned that our daughter, Kiana, would have Down syndrome when I was 20 weeks pregnant. We experienced all the emotions of grief that many people go through, while processing the reality of the child we would have. On top of learning about her little something extra, we found out she had a ventricular septal defect (a hole in her heart) and an enlargement of her liver. Adding to the stress of a difficult pregnancy was the challenge of giving birth in another country, in a language that was not my native language. I am from the United States, but my husband and I live in Japan. My husband is Japanese and thankfully could give me language support, but it was an emotionally difficult time.

When Kiana was born, she was almost immediately taken to the NICU, and we didn't see her for three hours. When we finally did see her, she was hooked up to so many tubes that we could barely touch her. I was so exhausted from

a 46-hour labor that I had to rest soon after seeing her. She was on breathing assistance and feeding tubes, and was being treated for jaundice. The doctors were monitoring her heart and white blood count because of transient myeloproliferative disorder or TMD, which had caused the liver enlargement that we had seen on the prenatal ultrasound. We couldn't hold her until a few days after she was born, and even then, it was only for a few minutes. The first time I fed my daughter, it was just to push a small amount of colostrum through her little feeding tube.

Despite the culture and language barriers, there were huge positives to giving birth in Japan. The average hospital stay for a new mom is five days, and it is a very pro-breastfeeding country. The nurses taught me how to massage my breasts to express my milk, how to use a pump, and eventually helped me learn to nurse my daughter. For the first few days, I hand expressed as much as I could into little syringes that I would then take up to the NICU. About two days into my hospital stay, my nurse told me I needed to start pumping every three hours, and brought me the pump so I could use it throughout the night. That pumping schedule would continue for the next five months until Kiana could take enough to thrive by directly nursing at the breast.

We had to wait two weeks until Kiana was off oxygen to try nursing for the first time. To be sure that she got enough, we weighed her before and after nursing. I remember the strange and wonderful feeling of nursing her for the first time. Until then, I'd felt as if I hadn't been able to give her any of the things a mother should. I didn't get to hold her as long as I wanted; I wasn't there to comfort her at night; I didn't even get to bathe her until a week after she was born. But, I was able to give her milk, and finally doing it without tube or bottle was amazing.

*KELLI & KIANA (CONTINUED)*

For the next six weeks, I went to the hospital every day and attempted to breastfeed for two out of her eight feeds. Her ability to nurse ebbed and flowed. Sometimes she would do great and nurse almost the whole meal; other times she'd appear to be nursing wonderfully, but when it came time to weigh her after 20 minutes, the scale would show a gain of less than an ounce. Other times, she'd fall asleep while nursing. Nevertheless, we kept at it. We were also trained to tube feed her so we could take her home, and six weeks after she was born, she finally came home.

Another blessing in Japan is the parental leave. We can take up to a year of paid leave, plus an additional two years of unpaid leave without being let go from a company. My husband and I took advantage of that, which was almost a necessity, as our days were filled with nursing, bottle feeding, tube feeding, pumping, and then washing all the supplies and equipment. After that was done, it was time to do it all over again. We finally cut out the bottle feeding because I wanted to focus on breastfeeding and because there are only 24 hours in a day! I dealt with milk, boobs, and baby most of the day while my husband was around to take care of household things, meals, and washing all the equipment (pump and tube feeding supplies).

Helping Kiana learn to breastfeed was not as simple as just putting her to the breast and letting her go with it. It required many pillows, trying many different positions, even a nipple shield at one point, as well as countless tears, and some amazing help from an occupational therapist friend. We also bought a scale and weighed Kiana before and after feeds to see how much she drank because we would have to finish her meal with the tube if she hadn't drunk enough.

I had never completely understood the reasoning behind putting Kiana on the tube. At first, it was because she was too weak to nurse on her own. Then it stayed in so she'd gain weight for a possible heart surgery. Then, when surgery was delayed indefinitely, the tube still stayed in. No doctor ever mentioned a plan to take it out, which started to worry me. I was determined to get Kiana off that tube, because I knew in my heart she could do without.

Kiana had done a great job nursing until at about three months when suddenly her intake dropped. Doctors ruled out any medical reasons, so there had to be a behavioral reason—she had figured out that she didn't need to nurse to feel full. We decided that fixing this behavioral issue was more important than weight gain at the moment, and we worked on weaning her off the tube. This was such a scary feeling for me! I had come to depend on the tube to ensure that Kiana was getting enough to eat and now we had to depend only on what she could take by mouth. Kiana had never experienced what it felt like to be hungry. Because of how long it took to nurse and tube feed, she almost always felt full. However, once the tube was out, she started to do great at nursing again! What a relief for me!

I'm so grateful for having been able to breastfeed my daughter. I didn't know if it would be possible, but I was blessed that no one told me she couldn't do it. Maybe they said it in Japanese, and I simply didn't understand them! But, she could do it. It was only the first of many times she has proven me wrong. She would breastfeed. She would sit. She would crawl. She would laugh. She would smile. She would be my daughter, extra chromosome or not.

## Mom Story

### BRIDGET & RYCKER



At 24 weeks gestation, I found out my son, Rycker, had an AVSD, which meant he had two holes in his heart.

We found out a week later, after we had an amniocentesis, that our son would also be born with Trisomy 21, more commonly known as Down syndrome. We were completely unprepared for the diagnosis, and the weeks following were a bit of a blur. I remember grieving: grieving the child I imagined, grieving the child who would get through life with ease, the child who would one day go to other kids' birthday parties because they wanted him there, not because they felt obligated to invite him, the child who would one day grow up to be independent and have a family of his own, the child who would one day make me a grandmother. At the time I didn't know much about Down syndrome or the strides that our

kiddos have made. I would soon learn that my fears were silly. The first glimpse I got of just how silly those fears were when I saw my son for the first time.

After being separated for a few hours, I was finally able to see my sweet boy but only for a few moments before he was whisked away to be transported to Children's Hospital. Due to complications I had from the c-section I remained in the hospital for three days. During that time, I pumped every two to three hours to ensure that my milk came in and would be ready for him for when we reunited. I hadn't always planned on breastfeeding or pumping; it actually wasn't until we got the diagnosis that I knew I had to give him the best nutrition possible, and I knew the way to do that was by giving him the nutritive benefits of my breast milk.

*BRIDGET & RYCKER (CONTINUED)*

After almost four long days, we were finally reunited. After the initial shock of all the machines, wires, and tubes, I really got to see my precious boy for the first time. Rycker had an NJ tube, which was used to give him my pumped breast milk in his first few days. When we were given the go-ahead to try breastfeeding, Rycker had quite a bit of trouble latching, but he was so determined. It wasn't until that first time that I got to hold him skin to skin that those fears I had during my pregnancy immediately dissipated. Just the sheer look of perfection in his plump round face, with his beaming eyes and pursed lips—how could I ever have imagined any other child to be mine? I knew at that moment that I was doing the right thing by breastfeeding, so we tried every single feed to get him to latch. Unfortunately, because his medical team didn't feel he was getting enough nutrients, we decided to try to give him bottles of my pumped breast milk. He took a little while to get the hang of, but after 16 days in the NICU, our little guy had gained enough weight that we could finally go home! Rycker went home at 4 pounds and 7 ounces.

I continued pumping, but after a few months, I noticed a decrease in my supply. I tried every single trick, tip, and trade to increase my milk supply. Fortunately, after a few weeks of consistently pumping every two hours, along with herbal supplements, I was able to increase my supply from 6 ounces a day to almost 30 ounces. Shortly after that, we were given the okay to try breastfeeding again. So, we did. Rycker wasn't really keen on the idea; my letdown wasn't fast enough for him, and he would pop off my breast every few minutes and scream his head off. We went in for a breastfeeding assessment with a lactation consultant at our pediatrician's office. She observed our breastfeeding session and by the end, said that Rycker was a "disorganized feeder" and that we "should just stick to bottle feeding" him my breast milk. I left the office that day in tears. I had never felt more determined in my life to prove someone wrong. We had been continuously told by multiple doctors, experts, and everyday people "Oh, he will never breastfeed, he has low tone and a lazy latch" or "What? You think you can actually breastfeed a baby with Down syndrome?" or "Breastfeeding a baby with Down syndrome just isn't possible!" Well, these people obviously don't know me or my son. Immediately after that, we got to work. I put Rycker to breast every single night to start, and then every morning and night, just to get him into a routine and show him another way to get his mama's milk. There were times he would scream his head off and times I was on the verge of screaming my head off, too! After almost 3-4 weeks of constantly and consistently putting him to breast, Rycker breastfed for 15 minutes for the first time, uninterrupted! We did it! My baby breastfed! After that, there was no stopping him: he breastfed every night and morning, and we even had a few days of cluster feeding, which were the best days of our journey.

## Mom Story

### DOERTE & ELLA



Ella was born in September 2014. She was hospitalized for ten days after her birth because she had very bad jaundice and her blood counts were out of whack. She had an NG tube, so I pumped so much breast milk that the whole fridge in the hospital's nursery was filled with bottles of my milk. The breastfeeding consultant and I did not succeed in getting her to latch, which was frustrating. She came home after ten days, and we continued to feed her breast milk through the bottle for the first two months.

I was busy pumping around the clock. We did not try to continue to get her to latch because I had read that if a baby does not latch in the first two weeks, it's too late. Besides, my mother-in-law from Singapore was staying with us for two months, and she was so happy to bottle-feed Ella. My mother-in-law is from a generation where mothers were given a drug to stop the breast milk. My husband

only got breast milk for one to two weeks. Babies were then transitioned to formula. It was not considered appropriate to take your breasts out even in the privacy of your home, and certainly much less acceptable to do so when you were out and about in public. My mother-in-law confirmed this sentiment. I was shy around her with anything regarding breasts and breast milk.

So, I continued pumping, and my mother-in-law eagerly bottle fed Ella for the first two months. I felt shy around her, so I pumped in privacy, feeling very alone. I pumped every two to three hours because I was afraid of getting milk ducts or mastitis.

*DOERTE & ELLA (CONTINUED)*

I was sad that I couldn't breastfeed Ella, but I was so happy that my mother-in-law bonded so well with my baby with DS. My husband had kept the diagnosis hidden from his parents for most of our pregnancy because he was afraid of judgment from his family.

My mother-in-law was scheduled to leave soon after Thanksgiving to return home, and I was newly motivated to give breastfeeding another try, because soon I would have no more help. It seemed daunting to pump around the clock, wash the supplies, bottle-feed every 2-3 hours, wash the bottles, then pump again. I was also tired of not being able to go anywhere because I had to pump so frequently. Once I pumped in the bathroom of a lecture hall at Stanford University because we really wanted to attend an event by the Silicon Valley Down Syndrome Network. The whole trip lasted four hours. My breasts were swelling and hurting. I finally pumped in the only semiprivate location I could find that had an electric outlet: the public bathroom next to the lecture hall. Parents and kids passed by me while pumping. I felt I had to explain all the time. It was a strange feeling. I did not want this anymore.

The next day I started to hold Ella up to my nipples again, trying to remember all the useful tips I had received from the breastfeeding consultant in the hospital. It went badly. She screamed, my nipples hurt, my breasts were swelling. I went back to the pump. We tried again with the same result. I stayed calm and tried again and again. We finally made it to a local breastfeeding group. The leader guided Ella's head gently, and she got a few drops of breast milk. Hurray! Ella seemed to understand what she had to do. She fell off frequently and failed to get milk at the next attempt and the next one. However, I had new hope.


I went home and tried and tried, and Ella got better and better. Finally, after about ten days of reintroducing breastfeeding, Ella was getting satisfying meals. From then on, she got a mix of breast and bottle-feeding. It was such a relief to have the freedom of breastfeeding. There were fewer bottles to wash, less pumping during the night, more going out, and being able to breastfeed her on the go. What a relief!

After a year of bottle and breastfeeding, Ella absolutely refused all bottles or sippy cups. She demanded breastfeeding exclusively. It was the only thing that would calm her down, or get her to sleep at nap time and bedtime. At 3½ years old, Ella is still nursing three times a day, and I am so grateful that we persevered!

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*Julia Grace waiting patiently for her mother's milk*

## Pumping and Hand Expression

MARSHA WALKER, RN, IBCLC

Depending on your and your baby's situation, you may wish to or need to express your breast milk rather than having your baby nurse directly. You may need to begin hand expressing and pumping your milk while you and your baby are still in the hospital or later when you have returned home. While expressing milk may not be as enjoyable as having a cuddly baby at your breast, you know that you are giving your baby the very best food. Your breast milk not only provides your baby with complete nutrition but also helps protect him against many diseases and illnesses. Research shows that breast milk benefits your baby's immune system. Most of the immune system resides in the gut (intestines), and breast milk creates an environment that makes it difficult for disease-causing bacteria, viruses, and fungi to live, and for toxins to cross out of your baby's gut and into the rest of his system. Even if your baby is not able to nurse directly at your breast, your milk reduces the risk of common conditions like ear infections, as well as more serious diseases and conditions like diabetes, pneumonia, gastrointestinal infections, and Sudden Infant Death Syndrome. Breastfeeding can help cut down on doctor visits and hospitalizations as well as days missed from work to care for a sick infant. You benefit from your breastfeeding relationship as well, with reduced risk of reproductive cancers, type 2 diabetes, cardiovascular disease, and high blood pressure. The time spent in expressing your milk is a wise investment with dividends that pay off in good health for both you and your baby.



## HOW DO I ESTABLISH MY SUPPLY IF MY BABY CAN'T NURSE DIRECTLY?

Many things can happen after you have your baby that may affect your breastfeeding plans. While some infants with Down syndrome can feed directly from the breast with few problems, other infants may have trouble and/or have more complicated health issues that allow only partial or no feeding from the breast, at least initially. What you do in the first three days following delivery can help you make more breast milk later on. The examples below may help you get things off to a good start:

- **If your baby can latch to the breast but only partially breastfeed**, you will need to express your *colostrum* during your hospital stay and pump your breast milk after you and your baby are discharged. Colostrum is the first milk that is produced after birth. It is rich in nutrients that help to establish your baby's good gut bacteria. Hand expression is often more effective at removing colostrum than an electric pump. Hand express your colostrum after you try breastfeeding your baby. Do this as many times as you can (six to eight times a day is ideal) and feed your baby this colostrum by spoon or syringe.
- **If your baby cannot feed from the breast**, or is in the special care nursery or in the neonatal intensive care unit, you will need to start expressing your colostrum as soon as possible after birth. Mothers who express their milk within one to three hours after delivery find that their milk comes in faster, and they have more milk than mothers who wait later than six hours. Use your hands to express colostrum as frequently as possible during the first 24 to 48 hours after your baby's birth. Ask that your baby be fed this fresh colostrum. In addition, using the hospital's double electric pump, express milk from both of your breasts at the same time, six to eight times per day for 15 minutes, every day. While using the maximum COMFORTABLE vacuum on the pump, massage, and compress each breast in turn while pumping. This is called *hands-on pumping*.
- Ask the hospital's lactation consultant to create a feeding and pumping plan while you are in the hospital. This should be a written plan, and another written feeding plan should be developed specifically for your situation before you go home. Ask your hospital's lactation consultant to help you arrange to have a lactation consultant visit you at home. During such visits the lactation consultant will work with you and your baby towards full feeding at the breast by helping your baby achieve a deep latch, monitoring effective milk transfer, and assuring adequate nutrition for good weight gain. The lactation consultant should be an International Board Certified Lactation Consultant (IBCLC). The lactation consultant can weigh your baby and adjust the feeding and pumping plans as necessary.

## Benefits of Pumping

- Breast milk is good for four hours at room temperature. If you have to go out with your baby, pump right before you leave and carry your milk with you. See appendix or [www.cdc.gov](http://www.cdc.gov) for full breast milk storage guidelines.
- Many moms have such a good supply when pumping that they are able to donate milk to other babies who may need it. It is gratifying to know that your milk has not only benefited your baby but other babies as well. Visit [www.hmbana.org](http://www.hmbana.org) for information on donating your milk.
- If you pump and give your baby breast milk, other family members can help you with feeding time.

## Quick Tips for Establishing Your Supply While Pumping

Establishing a milk supply if your baby is not able to feed at the breast can be a challenge, but it CAN be done! If your baby is not able to latch right after birth, you will need to start expressing colostrum, ideally within one to three hours after he is born.

- Hand expression can be more effective at removing colostrum/milk in the first 24 to 48 hours. Visit [www.juliasway.org/resources](http://www.juliasway.org/resources) to find videos to help you learn how to hand express your colostrum and breast milk.
- There is some debate about how long it takes to fully establish a breast milk supply, but there is research that shows that milk levels at two weeks may be a good indicator of what your future milk production will be. Pumping 8 to 10 times a day for those first few weeks will help to ensure a full supply later. Aim to pump every 8 to 10 times in a 24-hour period. For example, most moms find it beneficial to take a 5-hour pumping break overnight to get some rest. Even if you are not able to follow these guidelines perfectly at the start, it may still be possible to increase your supply by pumping frequently as late as 3 to 4 months after your baby's birth.
- Research indicates that milk production is the highest in the morning and starts to fall throughout the day, so it is very helpful to pump first thing after you wake up in the morning if you are trying to build a stash of milk for your baby if, for example, you will be returning to work, or if you anticipate that your baby will need extra calories.
- A multi-user pump can help establish your supply in the first few weeks. These types of pumps generally have a more efficient suction pattern and a motor designed to handle heavy-duty use.
- Looking at a picture, watching a video, or having a piece of clothing that smells like your baby while you pump can all encourage letdown.
- Some women are more responsive to hand expression even after the first few days, so experiment to see what works for your body.

- You will need a breast pump after you go home, which should be arranged before you leave the hospital. Even if state and/or federal law may require insurance companies to cover the cost of a breast pump, some of the pumps approved by your insurance company may not be strong enough to establish your milk production if your baby is not breastfeeding. You may need to ask your pediatrician to prescribe a multi-user double-electric pump. If your insurance plan does not cover this type of pump, you can rent one from a local medical supply company.

## HOW DO I CHOOSE AN EFFECTIVE PUMP?

There are many breast pumps on the market including single-user personal electric pumps, multi-user electric pumps (often called hospital-grade pumps), pumps that run on batteries, and hand (manual) pumps. If your baby is not feeding at the breast, your best option to establish your supply is to obtain a multi-user, double electric breast pump, either through your insurance plan or renting from a medical supply company. These machines pump 40 to 80 times per minute and have controls that allow you to adjust the level of vacuum and the speed of the pump. Some allow you to program the pump, have pre-set controls, or have multiple settings that vary the pumping speed before and after your milk lets down.

### Tips for Choosing a Good Pump

If you will be pumping long term or if you need to establish your breast milk supply with a pump because your baby cannot nurse directly, it is important to use a pump that has the following features:

- Pumps 40 to 80 times per minute
- Has controls that allow you to adjust the level of vacuum and the speed of the pump
- Has a long warranty period
- Has a closed system that includes features to prevent the milk from being drawn into the pump or from being contaminated by tubing or room air
- Can be easily taken apart and cleaned

Personal use, single-user pumps are a good option after your milk supply is well established, between 2 to 4 weeks after the birth of your baby, when you are producing enough milk to meet his needs, or when you seem to have reached your maximum milk production. These pumps can often use multiple power sources including household electricity, a battery pack, or adapters for use in a car. Lightweight and very portable, these pumps are designed to be used by only one person since they have no protective filters or other means to protect from contamination. Personal pumps are made by many different companies and are often covered by insurance.

It is not always easy to find time to sit and pump milk, so some mothers use a hands-free pumping system. This allows them to move around, care for other children, and generally stay mobile while pumping. These should be used after your milk supply is well established.

To save money, some mothers consider sharing a pump, are given a used pump, or think about purchasing a used breast pump. Be cautious, as the Food and Drug Administration (FDA) recommends that used pumps not be shared or resold. Personal use breast pumps cannot be sterilized between users, even if you use a new collection kit and flanges. There is a risk that milk from the previous user could have entered the motor, allowing bacteria, mold, and viruses to grow and be transmitted back to the next user. In addition, personal-use pumps have a motor that usually only lasts about a year with full-time use. By relying on a used pump, you take a risk that the motor no longer operates at peak function, causing a loss of vacuum or efficiency, and could reduce the amount of milk pumped, negatively affecting your milk supply.

## HOW DO I KNOW I HAVE THE RIGHT SIZE FLANGES?

Once you have a breast pump, the next step is to make sure the flanges fit your breast. The *flange* is the funnel-shaped part that is placed on the breast and into which the nipple and some of the areola is drawn when the pump is operating. Some of the pumps come with a complete collection kit, or you may need to purchase a collection kit separately. The correct size flange helps the pumping to be both comfortable and efficient. If you have a nipple size of approximately 20.5 mm (or the size of a US nickel) or larger, you may benefit from using a larger than standard size pump flange. This is because nipples tend to swell during the pumping process. The standard size flange that comes with a pump is usually 24 mm (or the size of a US quarter). Usually, a flange that is 3-5 mm larger than the diameter of your nipple before a pumping session and 1-2 mm larger after a pumping session is sufficient. Just as breasts come in different sizes, so do pump flanges. Visit [www.juliasway.org/resources](http://www.juliasway.org/resources) or see information in the appendix for help with finding the best fit for your breasts.

Nipples tend to swell a bit during pumping. Your nipple should be able to stretch without rubbing against the sides of the nipple tunnel on the flange. The flange is too small if:

- Your areola cannot move into the tunnel.
- Your nipple is sore or tender during or after pumping.
- The base of your nipple turns white when pumping.
- Any damage to the nipple or areola occurs during pumping, although this may also indicate that the vacuum is too high.

Too tight a fit squeezes milk ducts and does not allow for effective milk removal. If this is happening, you may need a larger flange. Incomplete drainage can lead to low milk supply, plugged ducts, and *mastitis* (an inflammation of the milk duct, usually due to a bacterial infection).

If you cannot obtain a good fit with a different size flange, you could try using a Pumpin' Pal® insert ([www.pumpinpal.com](http://www.pumpinpal.com)). These flanges do not have the hard ring at the entrance to the nipple tunnel, place less pressure on the nipple ducts as they are drawn into the flange, and are tapered to give some mothers a better fit and allow them to sit upright to pump instead of leaning over.

## PREPARING TO PUMP

Before you use your pump, wash your hands thoroughly with soap and water. Assemble your collection kit, making sure that the tubing is not moldy, wet, or soiled. If tubing is wet, attach it to your pump and run it for a few minutes until the water has cleared up before you use it. If tubing is moldy or soiled inside, discard immediately and use new, clean tubing. If you are pumping with a multi-user pump at the hospital, wipe down the countertop, the pump, dials, and power switch with a disinfectant wipe or solution before you use the pump.

## CLEANING YOUR BREAST PUMP PARTS

It is essential that all of the parts of the pump kit that come in contact with your milk are thoroughly cleaned after each use. Read the cleaning instructions provided by the manufacturer. Take apart the entire collection kit, including the flanges, tubing, valves, membranes, and connectors. If it can be taken apart, take it apart. Rinse the parts under running water to remove milk residue and clean the pump kit as soon as possible. These parts can be cleaned in a washbasin

with soap and hot water. Avoid putting the pump parts directly in a sink as germs can lurk in sinks and drains. The small basins, frequently given out by hospitals, are the perfect size for washing pumping parts and are usually easily available. Scrub parts with a bottlebrush, especially the areas that connect one part to another, and rinse well. Allow the parts to air dry, or dry them off with a clean towel. If the manufacturer recommends, you can place all of the pump parts in your dishwasher on a sanitizing cycle. Small parts should be placed in a mesh bag or little closed-top basket. Allow the parts to completely dry before storing in a food storage bag or container. See the appendix for detailed cleaning instructions or visit [www.cdc.gov](http://www.cdc.gov).

### Mom Tip

If you can't nurse your baby and have to pump, this is the perfect time to recruit your partner or family member to help. For example, allow your husband, partner, or other family member to take one middle-of-the-night feeding so you can have a longer stretch of sleep.

## PUMPING AT HOME

If feedings are not established at the breast by the time you are discharged from the hospital, you will need to continue to pump your milk at home. Aim to pump 750-800 mL (25-27 ounces) per day by 7 to 10 days after your baby's birth. The most important time for establishing an abundant milk supply is during the first 14 days, so spending lots of time pumping during this period will benefit you and your baby later. Pumping 8 to 10 times per day during the first two weeks or until your milk supply is well established is the usual recommendation. While this sounds good on paper, it might not be so easy if you or your infant have continuing medical problems, or if you have other children at home to care for. Here is where asking for help comes in. Ask family or friends to help with household chores, contribute to caring for your other children, or run errands to allow you the time you need for expressing your milk. Sometimes faith-based organizations, churches, youth organizations, and other community services are sources of much-needed help. Pumping times do not need to be evenly spaced throughout the day and evening. Some mothers pump once at night during this two-week period when they naturally wake to use the bathroom or when their breasts feel full. Pump more frequently during the day. There are also pumps on the market that are hands-free and allow you to pump without having to sit down or interrupt other activities.

Begin each pumping session by double pumping and simultaneously compressing your breast and massaging any firm areas. When the milk flow stops or slows down, turn off the pump, massage the breasts for a minute or two, and then resume either pumping or hand expressing until no more milk can be removed. Using this technique early on may allow you to maintain higher milk production later with less frequent pumping. You can store your milk in BPA-free bottles, plastic bags that are made specially to store breast milk, or in a breast milk storage system. Use the chart on the next page as a guide for how long you can safely store your expressed milk. These are the latest guidelines available as of the printing of this book. Visit the Centers for Disease Control and Prevention's website at [www.cdc.gov](http://www.cdc.gov) for the latest guidance regarding storage and handling of breast milk.

# Human Milk Storage Guidelines

	Countertop or table	Refrigerator	Freezer with separate door
Storage Temperatures	77° F or colder (25° C)	40° F or colder (4° C)	0° F or colder (-18° C)
Freshly Pumped/ Expressed Human Milk	Up to 4 hours	Up to 4 days	Within 6 months is best, up to 12 months is acceptable
Thawed Human Milk	1-2 hours	Up to 1 day (24 hours)	Never refreeze human milk after it has been thawed

These guidelines are for healthy full-term babies and may vary for premature or sick babies. Check with your health-care provider. Guidelines are for home use only and not for hospital use.



United States Department of Agriculture  
Slightly Revised July 2018

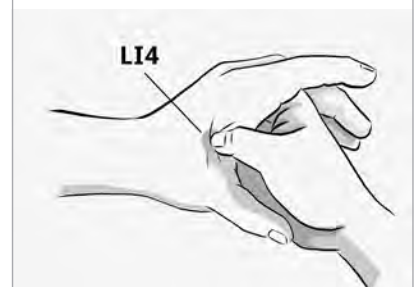
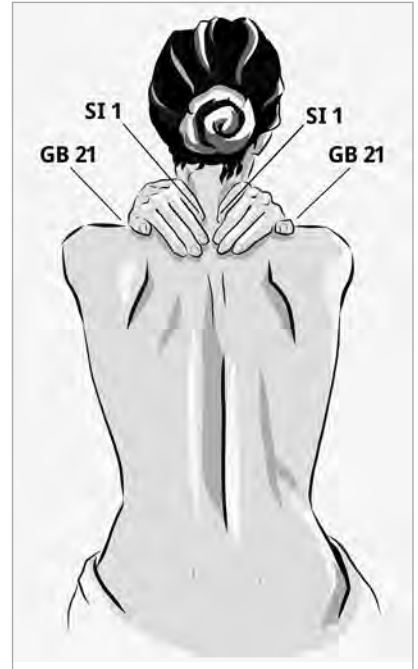
Find more breastfeeding resources at:  
[WICBreastfeeding.fns.usda.gov](http://WICBreastfeeding.fns.usda.gov)  
[cdc.gov/breastfeeding/](http://cdc.gov/breastfeeding/)

## GETTING THE MOST OUT OF YOUR PUMPING SESSIONS

Julia's Way surveyed mothers of babies with Down syndrome (DS) and discovered that almost 70% of these mothers have had to pump at some point during their baby's breastfeeding journey for reasons other than returning to work (for example, until their baby was strong enough to nurse, while waiting for heart surgery, or while their baby was recovering from surgery). Pumping can be tiring, and it may be challenging to establish your breast milk supply if your baby cannot nurse directly, but it can be done! If your milk production at 10 days is 350-500 mL (11-17 ounces) or less than 350 mL (11 ounces) per day, you should take measures to boost your supply. The list below is not intended to be overwhelming but is aimed at helping you maximize your breast milk supply. These techniques do not need to be used at every pumping session, but consider using them occasionally to increase your milk supply.

- If you have not been pumping at least six times per day, increase your pumping frequency. To establish your supply, more frequent pumping is more effective than longer pumping sessions.
- If nipples are cracked or bleeding, hand expression may be a better option until they are healed.
- Warmed breasts can often yield more milk per pumping session. Consider applying a warm compress or breast pad to your breasts for several minutes before pumping. Alternatively, run your pump flanges under hot water, and place them on your breasts when they are comfortably warm.

- Listen to relaxing music while you pump. Relaxing music has been shown to have a positive effect on milk supply and the fat content of your milk. Listening to music while watching a slideshow of your baby was shown in the same study to be even more effective in increasing breast milk removal.
- Massaging your breast for a few minutes before you start pumping can encourage letdown and increase output. Research also suggests that massaging while pumping may increase milk output. You can wear a hands-free bra to hold the flanges in place while you massage each breast, or you can place your arm across the flanges to hold them while you massage.
- Acupuncture is reported to increase milk production.
- As long as it does not cause you pain, consider turning up the vacuum pressure during the two-minute letdown cycle to help your milk start flowing. After the letdown cycle is over, you can turn down the pressure as needed.
- Try the “milkshake!” Lean forward and let your breasts hang down and gently shake them back and forth to stimulate the breasts and release the milk droplets from the walls of the milk ducts.
- Hypnosis or guided imagery may help some mothers.
- Acupressure has been shown to increase milk output. The research article studying acupressure and milk supply used the SI 1, LI 4, and GB 21 points. All three points are easily accessible and can be done while pumping. SI 1 is very helpful for low milk supply as it helps improve mammillary filling and increases lactation and prolactin levels. The GB 21 point helps promote the milk letdown reflex. Acupressure practitioners generally recommend that you stimulate these points 2 to 3 times a day.
- Check that the pump flange is not too small, which may be restricting milk flow. Nipples swell during pumping so changing to a larger flange part way through the pumping session may be helpful.
- Changing to a different pump may be helpful for some mothers.



*Acupressure Points:*

**SI 1** is on the outside corner of the pinky nail.

**GB 21** is at the highest point on the shoulder, midway between the spine and the shoulder.

**LI 4** is located in the muscle between the thumb and finger.

*Illustration ©2019 Julia Eva Bacon*



- Make sure that your pump is operating at peak efficiency and that it does not require maintenance for reduced vacuum. A lactation consultant can check this with a vacuum gauge.
- Make sure that the entire flange is touching the breast. Vacuum cannot be properly established if the entire flange is not in contact with the breast. Check that the flange section under each breast is completely touching the breast. Check your flange size. Sometimes going up or down a size will stimulate the nerves behind your areola more effectively, thereby allowing for a better and more productive letdown, which leads to more milk. Visit [www.juliasway.org/resources](http://www.juliasway.org/resources) or the appendix for help finding the proper fit for your flanges. It may also help to be assessed by a lactation consultant.
- Make sure your pump kit is assembled properly, and all valves and connectors are in place.
- Try power or cluster pumping: Pump for 20 minutes, and rest for 10 minutes, repeat this cycle for one hour. Repeat this daily until you see a boost in your supply. If you would like, you can power pump more than once per day to simulate cluster feeding, something that babies naturally do. A more detailed look at power pumping can be found at: [www.livingwithlowmilksupply.com/power-pumping-to-increase-milk-supply](http://www.livingwithlowmilksupply.com/power-pumping-to-increase-milk-supply)
- Ensure that you are not taking medications, supplements, or herbal products that could reduce milk production. Hormonal birth control, pseudoephedrine (Sudafed®, Zyrtec D®, ethanol/alcoholic beverages, bromocriptine, ergotamine, cabergoline, and antihistamines are examples of medications that can interfere with milk production.
- Some research suggests that smoking can interfere with milk production and the letdown response. Please consider stopping smoking while breastfeeding your baby. A medical professional may be able to assist you if you do decide to stop smoking.
- Some moms find it helpful to cycle through the letdown phase twice during a pumping session. If you can elicit a second letdown, you can increase your output and supply. On most pumps, the initial letdown cycle lasts two minutes. Pump for 6 to 7 minutes after that initial let down cycle, and then push the button to go through the letdown cycle again, and pump for another 6 to 7 minutes.

## GALACTAGOGUES

A *galactagogue* is something that you eat or drink that is intended to increase milk production. Many cultures have special foods or drinks that are traditional for new mothers to consume immediately after birth. Research is beginning to show that those traditional foods frequently have a positive impact on milk supply. Galactagogues can be very helpful in improving your milk supply, but it's important to remember that they do not work on their own; they have to be coupled with increased demand (more sucking by your baby or more pumping) for maximum effectiveness. There are several different galactagogues available. This section is not an endorsement

of any supplement or herb for this purpose, and we strongly recommend that you consult your doctor or lactation consultant before using any herbal supplement, tea, etc., to increase your supply. Galactagogues have no standardization as to dosages or indications where they may best be used, and many do not work at all.

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**It is important to note that the different galactagogues work for different causes of decreased milk supply so it may take some experimentation to see what works best for your body.**

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Before taking any of these galactagogues, make sure that you have tried the suggestions in the section “getting the most out of your pumping sessions” to boost your supply. Some galactagogues may require a physician’s prescription. Many of the preparations that mothers take to increase milk production have little to no evidence behind their use. Some have potential side effects or warnings that need to be observed. Some galactagogues work better than others depending on the condition that is contributing to low milk production, and they are more effective when they specifically target the cause of low production. Fenugreek, for example, acts on sweat glands to increase secretions, and since the breasts are secretory glands, this herb can sometimes increase milk output. Fenugreek can also lower blood sugar, so if you are diabetic, be sure that you mention this to your medical provider before starting this supplement. Goat’s rue has been linked to improved milk production because of its supposed effect on improving mammary gland growth.

There are two prescription medications that may increase milk production because they affect prolactin levels, although neither drug’s primary purpose is to boost milk supplies. Metoclopramide (Reglan®) is a gastrointestinal medication that has been shown to increase milk production in some mothers. It is used with caution as it has the potential to cause depression and involuntary body movements, and it should not be used if you have a history of depression. It can also cause fatigue in some mothers. Domperidone (Motilium®) is also a gastrointestinal drug that has been shown to increase milk production. It is not available in the United States but can sometimes be obtained from a compounding pharmacy or ordered from outside of the country with a prescription. Caution is necessary if you are also taking antacids, antifungals, macrolides, HIV protease inhibitors, or monoamine oxidase inhibitors. You should not take this medication if you have a heart condition like an arrhythmia or other heart anomaly. Domperidone, like Metoclopramide, does not work for all mothers and may not work unless your prolactin levels are low. You should consult with your physician about these medications.

Moringa is a nutritional supplement that is often used to attempt to increase breast milk supply. *Moringa oleifera* is a tree that grows in tropical areas of the world, including California and Florida. Some research shows that the leaves may increase breast milk production. Moringa leaves are very nutritious and contain vitamins, minerals, proteins, and antioxidants, which can protect your body from illness. The leaves can also increase energy and lower cholesterol. Moringa can be taken in capsule, tincture, or powder form.

Lactation cookies, oatmeal, milkshakes, and herbal lactation bars are all on the market, but there is no real evidence of their effectiveness. These foods generally contain mixtures of various herbs, but there are no standards about what is actually effective. Just because herbals are plant-based and/or organic does not mean that they are benign. You should check with your healthcare provider to make sure that nothing you wish to try interacts with any other medication or supplement you might be taking. Too much of these herbals can produce undesired side effects. Common herbal galactagogues include alfalfa, blessed thistle, fennel, fenugreek, nettle, garlic, goat's rue, milk thistle seed, and shatavari. These supplements are available either as single ingredients or mixed with other herbals. Various combinations of these herbals can be found in teas marketed for nursing mothers and can also be found in tinctures, which are more concentrated than the teas. The evidence for their efficacy is mixed.

## WHAT IF SUPPLEMENTATION IS NEEDED?

Sometimes extra nutrients are needed if a baby is premature, or has cardiac or medical issues that require more calories. If supplementation is needed in the hospital, you can ask that banked donor human milk is used instead of formula. Colostrum supplements can be given by spoon, dropper, syringe, or cup. Supplements can also be given through a tube feeding device, called a supplemental nurser, that is placed on your breast so that baby receives the supplement while nursing. The tube feeding device can also be attached to a finger, and the supplement can be finger-fed to your baby. A formula supplement might be used if no colostrum or banked donor human milk is available. This, too, can be given by the above methods. Supplements may still be needed after you are home with your baby until he is receiving most of his nutrition at the breast.

If your baby just needs more calories and if you can express abundant amounts of milk, you can skim the fat layer that has risen to the top of a refrigerated container of your milk. You can do this with a syringe, a dropper, or a spoon, like skimming fat from a sauce. This fat layer is very calorie-rich and may encourage appropriate weight gain. For more information on this process see steps for skimming milk without a centrifuge in the heart chapter.

Extra calories can also be provided using high-calorie formulas. If infant formula has been recommended, it is best to use it as a separate feeding and not mix it into expressed breast milk because infant formula might interfere with the anti-infective properties of breast milk when mixed together.

While bottles are typically used to supplement breastfed infants, sucking on an artificial nipple may reinforce the narrowing of the baby's palate, which infants with Down syndrome are already prone to, and weaken the masseter muscles, which are involved in sucking. If you would like to avoid using an artificial nipple, you could consider cup feeding or finger feeding your baby, if allowed by his medical team.

The first months after the birth of your baby will be a busy and stressful time in your life, and breastfeeding and expressing milk will take time, effort, and lots of patience. The breastfeeding window is a relatively short period, but breastfeeding will provide a lifetime of benefits for the health of both you and your baby. Don't hesitate to seek help. An IBCLC experienced in working with babies with special needs can be an invaluable source of support during this time. Create your support system and treasure your child.

### Making Pumping More Efficient

If you have it in your budget, consider purchasing these items that may make pumping a little easier:

- A hands-free pump or pumping bra.
- An AC adapter to allow you to pump in the car (helpful when driving to work or to doctor's appointments, which you may be doing frequently in the first few weeks).
- A second set of pumping parts, so you don't have to wash as often.
- Breast pads that you can freeze or heat up in the microwave can be helpful. Cold helps if your breasts are engorged, and heat applied to the breast prior to pumping may help remove more milk.

## Mom Story

### CLAIRE & FINN



My son Finn was born in January, a much-wanted second baby. I tried and tried to nurse him, but he just did not latch on. This devastated me. Not only was I coming to terms with our birth diagnosis of Down syndrome, but I had nursed my older son for 26 months and so desperately wanted to do the same for my Finn.

In the end, I decided to do the next best thing by expressing my milk and feeding it to Finn in a bottle. I found it hard work to fit in the numerous pumping sessions, especially with a 3½-year-old running around, but I knew that was what I wanted to do. I tried to get Finn to the breast regularly during this time, but nothing seemed to work. I felt desperate on days when my supply was low, and I had to give him formula. It broke my heart. It may sound dramatic, but I just did not want to go down that road. My elder son never had a drop of formula, so why should Finn?

I found a few bits of information that said it could take six months before a baby with Down syndrome learned to breastfeed, so I set that as a time limit. While on holiday in Spain, at 5 months old, my son latched on! He fed, and I cried my eyes out. It was the most special moment. After a bit of practice, he was feeding like a pro, and we ditched the pump and the bottles. He is a year old now and is still going strong with nursing! The pumping was tough, but we did it, and I am so proud of my gorgeous little man.

## Mom Story

### CHRISTINE & RORY



My daughter, Rory, was born full term with complex congenital heart defects and Down syndrome. We had a prenatal diagnosis, so nothing was a surprise; I was prepared and eager to provide milk for her.

For the first two months, I pumped exclusively while she recovered from her first two heart surgeries. At two months old, Rory breastfed for the first time. She immediately took to the breast, which came as a shock because she really struggled with bottle feeding. We were still in the hospital, and her entire team was elated by how she took to breastfeeding.

Unfortunately, after a couple of blissful days, we realized she wasn't actually transferring milk. She enjoyed breastfeeding so much that we kept it up anyway, with the hope that one day she would be able to transfer milk successfully. In the meantime, our routine was to breastfeed first, then try bottle feeding, then we'd tube feed the rest of her meal, after which I would pump. Eventually, I learned to pump while bottle feeding and tube feeding, which cut back on time quite a bit.

At three months old, Rory was discharged from the hospital with a feeding tube. Her team wasn't terribly optimistic that she'd be able to eat by mouth, but they agreed to let us try at home. Eight days later, Rory started taking all of her feeds by mouth, via bottle. It was a tremendous milestone. She still wasn't transferring milk from the breast, but because she continued to be comforted by the closeness and action of breastfeeding, we kept chugging along.

Rory breastfed for comfort until she was 13 months old, at which point she lost interest. But she was still thriving on expressed breast milk! At 17 months old, she had her third and fourth heart surgeries in quick succession. While she was in the hospital, we learned that I was making high-calorie milk, which helped explain why Rory was growing so beautifully on just breast milk. Due to feeding issues, she continued to receive all of her nutrition from breast milk until she was more than 2½ years old. Since then, she has continued to take her breast milk by bottle, but she now eats some baby food as well. She is thriving, and I'm so grateful for how far breast milk has taken her. Rory is now four years old, and I am beginning to wean from the pump.

Since Rory breastfed non-nutritively, I essentially pumped exclusively from day one. We've had a few well-intentioned people express their sadness for us since we didn't end up with the breastfeeding story we had originally hoped for. But because I've pumped so much, Rory and I have been able to donate over 23,000 ounces (180 gallons) of breast milk to babies in need. So while we haven't been successful in typical terms, we've had an incredibly beautiful experience overall. All the credit goes to Rory. Her strength fuels me to keep going. She's worked so hard to get to this point, and I'm so grateful that I can still provide something to fuel her, too.

## Mom Story

### KRISTIN & ASHLYN



Breastfeeding my children has always been important to me. My first two babies had a relatively short nursing journey, as I had to go back to work after 12 weeks, and both decided they preferred the bottle once they started daycare. Having been chained to my breast pump so that I would have breast milk for each of them until they were one year old, I was very excited about my third pregnancy, because I was going to be able to quit my full-time job, and instead be a full-time mom with no pumping in sight!

We found out about Ashlyn's Down syndrome (DS) diagnosis following our 20-week ultrasound, which revealed several soft markers, and we decided to do further testing with the MaterniT21® test.

The first thing I did when we found out about Ashlyn's diagnosis was turn to the internet. Almost everything I read said that most babies with DS are not able to breastfeed. I was

sad and upset to think that the nursing journey I had planned for this baby would not happen.

I confided my fears and sadness to a friend one day over lunch, and by the next day, she had put me in touch with someone she knew at the La Leche League who sent me encouraging information. I thought I might be able to breastfeed after all, and I started having a little hope!

When Ashlyn was born, she surprised us all, weighing 9 pounds, 2 ounces, when we were all expecting a small baby! Shortly after she was born, a nurse suggested we try breastfeeding, and to my amazement, she latched on right away. She impressed everyone in the room! I don't think any of us expected it to go so well the first time.

By the next day, things were not going as well. Because she was such a big baby, they were constantly checking her blood sugar levels, which made her very upset, and then I was immediately expected to nurse her. She was either asleep by the time they got her back to my room,

*KRISTIN & ASHLYN (CONTINUED)*

or she would suck for a minute or two and then fall asleep at the breast. This went on for many feedings. On the second day, we got a visit from the best lactation consultant I could have asked for. When she came to our room, she had already researched breastfeeding babies with DS and was so supportive. She told me we were both doing great and that we just needed to keep trying.

Feedings went better once we left the hospital, and I allowed Ashlyn to set her own schedule. She could feed when she wanted to, and she wasn't as tired during feedings. However, she did not have a good latch, and she leaked milk out of her mouth. She also seemed to be taking in more milk than she could swallow at a time. The lactation consultant came to our house for a visit, and once again assured me that we would eventually succeed, and not to give up.

At her first visit to her doctor, Ashlyn was not gaining weight. I was instructed to stop nursing and strictly pump and bottle feed so we could monitor exactly how much she was eating. I was devastated once again. I worried that once she started getting bottles, I would not be able to go back to nursing. I had hoped to avoid pumping so much this time around, and here I was, pumping even earlier than I had with my other kids! Once again, my lactation consultant was so reassuring and told me that many babies are able to nurse again after being bottle-fed. I pumped exclusively for about a month before Ashlyn finally gained enough weight, and the doctor was comfortable not measuring her feedings.

Ashlyn amazed me again and latched on right away! She was still having an issue with milk leaking out of her mouth, which was very frustrating. I was worried that she wasn't swallowing enough and that she was going to lose weight again. I attended several breastfeeding support group meetings to get extra help, and to make sure she that was gaining weight. I even bought an infant scale so I could do weighted feedings at home to see that she was actually getting enough in her tummy!

Eventually, her latch got stronger, breastfeeding became so much easier, and she was no longer leaking half of it out of her mouth at each feeding! In the end, Ashlyn was my longest-nursing baby. She nursed until she was 14 months old, when I made the decision to be done.

Although I was very scared it would not go well, my breastfeeding experience ended up being a great one. I can't thank our awesome lactation consultant enough for being so encouraging every time things weren't going well. I was happy that I stuck with it, and had a wonderful experience with my baby!



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*Julia Grace feeding herself a strawberry*

## Child-Directed Feeding

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*Please note: The terms baby-led weaning and baby- or child-directed feeding are used interchangeably in this chapter.*

Breastfeeding is a baby-directed approach to feeding: Your baby shows you when she is hungry and stops nursing when she is full. Child-directed feeding is fundamentally empowering to the baby, and it seems natural to maintain this approach as your growing baby transitions from milk to solid foods: She continues to decide *how much* to eat, and as she becomes more capable, she starts to decide *what* to eat when given a choice of healthy options.

In contrast to breastfeeding, traditional bottle- or spoon-feeding is caregiver-directed. The baby is often encouraged to “finish the bottle” or “finish the jar” of food. This leaves the decision of how much to eat in the hands of the caregiver rather than the baby. By maintaining a baby-directed feeding approach as your child adapts to eating solid foods, you enable her to gain greater independence, become more attentive to when she is hungry and when she is full, and to develop crucial oral motor, fine motor, and self-feeding skills. Using a responsive feeding technique, such as baby-directed feeding, helps you to recognize your baby’s feeding cues and encourages you to only feed her only when she is hungry and to stop when she indicates that she is full.

Baby-directed feeding has been popularized by Gill Rapley and Tracey Murkett. They describe the technique in their book, *Baby-Led Weaning: The Essential Guide to Introducing Solid Foods and Helping Your Baby to Grow Up a Happy and Confident Eater*. The term baby-led weaning (BLW) can be misleading. It does not mean weaning from breast milk or formula, but refers to a process, usually taking place over the course of several months, in which a baby moves from breast milk to solid foods as her primary source of nutrition. According to Rapley and Murkett, “In baby-led weaning, the baby eats with the rest of the family, sharing the same nutritious and varied food. There’s no spoon feeding (by an adult) or specially made purees, and no persuasion or pressure. The baby chooses what to eat, how much, and how fast, and she feeds herself. At first, the food is offered in a way that’s easy for her to handle, for example, sticks or strips of food that are firm enough to hold but soft enough to munch. Then, with practice, she begins to manage more complex textures and shapes, and later to use cutlery. But it’s always the baby who sets the pace. During this initial period of weaning, there is no pressure for your baby to consume a certain amount of solid food because all of her nutritional needs are still being met by breast milk or formula. Your baby may continue to nurse for several months or more after this transition, but her primary source of nutrition will eventually come from solid foods.

This chapter is an introduction to child-directed feeding, and why and how it can be beneficial, especially for babies with Down syndrome (DS). It is not meant as an exhaustive reference, and we urge you to work with your baby’s medical team and specialists to ensure that this is a safe and positive experience for your baby and your family. Many babies with Down syndrome will need support from a feeding therapist to successfully transition to solid foods in this manner, so check with your baby’s pediatrician or feeding team before starting this process.

## **WHAT IS CHILD-DIRECTED FEEDING AND WHY IS IT A NATURAL TRANSITION FROM BREASTFEEDING?**

Traditionally, babies learn to eat in this order: liquids, purees, and then solid foods. In contrast, a strict baby-led weaning approach skips purees and moves directly to solids. Babies learn to feed themselves from the time solid foods are first introduced, and these solid foods are presented as graspable pieces, rather than as homemade purees or store-bought baby food. When you feed your baby pureed food with a spoon, all she has to do is open her mouth and swallow the smooth puree. Compare that with a baby actively feeding herself: she is engaging her core, working on fine and gross motor skills, practicing hand-eye coordination; and learning to move food around in her mouth. Additionally, she is beginning the process of learning about textured foods, like cottage cheese or lumpy mashed potatoes, through tactile and oral exploration. This learning

about textured foods is an essential part of development for any baby; a delay in this process may result in your baby developing a resistance to textures and eating a more limited variety of foods as she matures. By actively feeding herself, she is developing the necessary skills to become an independent eater.

It is important to note that the principles of BLW often need to be modified for babies with DS. However, even with a modified version, you can help your baby be an active participant by giving her a preloaded spoon or silicone feeder or allowing her to use her hands to pick up and manipulate food as you start to encourage feeding independence. She may sometimes require gentle guidance to get the food to her mouth, but the food should not be placed in her mouth for her.

## **BENEFITS OF CHILD-DIRECTED FEEDING FOR BABIES WITH DOWN SYNDROME**

Child-directed feeding may not be the right choice for all babies with Down syndrome, and can take patience and dedication on the part of their caregivers, but when implemented successfully, this method can have far-reaching effects. Along with breastfeeding, pre-feeding exercises, and therapeutic feeding techniques, child-directed feeding can foster improved oral motor and feeding skills and help your baby develop gross and fine motor skills that will serve her well in the future. Practicing baby-directed feeding daily even with one meal, or just a portion of a meal or a snack, encourages independence and allows your baby to eat alongside family members.

In addition to encouraging independence, this method of feeding provides several other benefits to babies with DS, who are at risk for a variety of health and developmental concerns. Choosing a baby-directed feeding approach when moving to solids transforms eating into a therapeutic activity. Historically, people have believed that babies with DS cannot breastfeed; however, we know that is not the case. Similarly low expectations have often led to babies with DS being spoon fed for an extended period of time, as it was thought that they were not capable of chewing table foods or eating independently. Unfortunately, these mistaken ideas persist in some corners of the medical field. Research suggests that there is a critical period in which to introduce new and textured foods, especially in populations where the baby may be predisposed to an extreme aversion to textured foods (for example, babies who have had frequent or sustained negative invasive oral procedures, such as nasogastric tube placement, suctioning, or intubation). For babies with Down syndrome, who can sometimes be sensitive to textures, extended spoon-feeding can actually lead to even greater difficulty transitioning to textured foods if this critical period is missed.

In short, baby-led weaning will help your child become a more independent eater. It will allow her to eat with family members and peers without needing to be fed by an adult, and it will positively impact her overall developmental skills as well.

Babies with DS can benefit from child-directed feeding in the following ways:

- **Obesity** – Children and adults with Down syndrome are at risk for obesity. Baby-led weaning allows your child to determine when she is hungry or full, which can decrease the likelihood of overeating. More research is needed, but early studies indicate that this may be a good way to help prevent childhood obesity.
- **Motor development** – Breastfeeding is a therapeutic tool for your baby, providing frequent exercise for her jaw, cheeks, and tongue, and fine coordination of the muscles of her face and jaw. Similarly, baby-led weaning can also provide therapeutic benefits. The constant hand-to-mouth activity required for self-feeding helps engage the baby's core every time she leans forward to pick up a food item. Repeated practice picking up food to self-feed can help your baby develop eye-hand coordination and fine motor skills as well, and progress from a raking gesture to a more refined pincer grasp.
- **Picky eating** – Breast milk has varied tastes, depending on what the mother has eaten. As a result, breastfed babies may be more receptive to a variety of tastes. Similarly, babies who are able to choose from a variety of tastes and textures of food from an early age may eat a wider range of foods later in life.
- **Sensory processing** – Early and frequent exposure to textured foods is important, and research has found that babies who begin to receive lumpy solids after ten months of age may have significantly more feeding difficulties than those who began earlier in life. If your baby was born prematurely, you should use his adjusted age. This may be especially true for babies who have underlying sensory issues, as is the case for some babies with Down syndrome, especially if they have a history of invasive oral procedures (intubation, suctioning, or nasogastric tube placement). The presence of these sensory-based issues can result in an aversion to feeding and difficulties adapting to texture. If their motor skills support safe nutritive eating, giving babies real foods from the time they are ready to transition to solids allows them to chew and move pieces of food around in their mouths, like soft solids and meltable solids, resulting in important sensory feedback. Baby-led weaning gives babies daily tactile and sensory experiences as they directly touch, taste, and smell their food, allowing them to gradually get used to new textures. Giving your baby the opportunity to explore her food in this way can make her more receptive to the new foods.
- **Oral motor/feeding skills** – Jaw strength and stability are required to bite and pull on food strips. With baby-led weaning, frequent exposure to whole foods allows babies ample opportunity to bite, chew, and learn to move food around in their mouths. They learn to lateralize food by using their tongue to move the food from the center of their mouth to their biting

surfaces to break it down before swallowing. Baby-led weaning also requires that babies learn graded biting and chewing, by biting off appropriately sized pieces from a whole food, using a controlled chewing pattern to break down the food completely prior to swallowing. This can be learned from frequently bringing food strips to their mouth, and learning to bite, pull, and tear pieces off with their gums and teeth. More refined chewing skills can be acquired by using meltable solids, foods that start off as solid food pieces but dissolve with saliva and break down easily with limited chewing, allowing the baby to practice taking small, controlled bites. In contrast, babies who are spoon fed for an extended period of time may have limited experience with or exposure to biting, chewing, and moving food around in their mouths.

## SEEKING HELP FROM A FEEDING SPECIALIST

You, your family, and your baby's medical team, if applicable, need to determine what works best for feeding your baby. If you decide that child-directed feeding is the best decision for you, there are written resources available, including Rapley and Murkett's book, and Rapley's website (see resources at the end of this chapter for more information). However, in-person guidance from a feeding specialist who has experience with this method is essential to ensure that it is safe and effective for your baby. It is important to work with a specialist who understands typical feeding development and how to help your child learn safe feeding skills. A qualified feeding therapist can be a speech pathologist or an occupational therapist. Your Early Intervention providers may be able to assist you with this as well. An experienced therapist will know how to make feeding modifications to ensure that your baby has a safe transition to solids. If you do not have access to a qualified feeding therapist to ensure that your baby has the skills necessary to transition to solid foods safely, you should not attempt this feeding approach with your baby with Down syndrome. If your baby has any of the following therapists, consider seeking their opinions as you start your baby's transition to solids:

- **Physical therapist (PT)** – A physical therapist can make sure that your baby is well supported in her high chair so that she can self-feed most effectively. Your baby needs stability while eating so she can easily bring her hands to her mouth and not get overtired while eating (due to using too much energy just to stay upright). Your baby's physical therapist will likely recommend that her high chair has a place for her feet to rest, which allows for greater stability.
- **Occupational therapist (OT)** – Besides helping with the initial stages of self-feeding, an occupational therapist can also show you modifications that will encourage your baby to use her hands and fingers to self-feed, and eventually to use utensils. Your baby's OT may even do food play to familiarize and desensitize your little one to unfamiliar foods and textures, especially if she has sensory issues.



- **Speech therapist (SLP)** – A speech therapist or speech-language pathologist can complete a task analysis, assessing for the foundational skills needed for chewing and cup drinking. This ensures the necessary skills are present so that your baby can safely attempt to eat more complicated food textures. An SLP can guide you in which foods to start with and what textures are safe for your baby depending on her specific challenges. If appropriate, an SLP will teach you how to facilitate lip, jaw, tongue, and cheek stability and mobility to help your baby develop the necessary skills to break down foods as she transitions to solids.
- **Registered dietitian (RD)** – An RD can determine portion size and recommend healthy proteins, fats, carbohydrates, and sources of micronutrients like iron for your baby, especially if she needs to gain weight, is overweight, or has issues with constipation.

## IS MY BABY READY FOR SOLID FOODS?

### Feeding readiness skills: preparing to eat

Many babies with Down syndrome have low muscle tone, which can make it difficult for them to sit up on their own. Without the necessary stability required for sitting, they do not have the base or foundation for feeding skills. Since stability of the mouth depends on the strength of the core, trunk, shoulders, and jaw, a baby who is unstable in a seated position cannot work on or safely use the skills necessary to manipulate and break down food. This means that they may use compensatory strategies like mashing food with their tongue, or using a tongue protrusion-retraction pattern or reverse swallow to manipulate and break down their food. Additionally, babies with Down syndrome are at risk for feeding and swallowing issues, including silent aspiration. For these reasons, before starting the transition to solid foods, it is essential to ensure that your baby has foundational feeding skills, including postural stability and the ability to correctly use her lips, jaw, cheeks, and tongue to safely support feeding. A speech pathologist who specializes in feeding or a qualified feeding therapist can do a pre-feeding assessment of these foundational feeding skills. In this assessment, your baby's feeding therapist will ensure that your baby has all of the skills necessary to be a safe and efficient eater. The therapist will evaluate your baby's lips, tongue, cheeks, and jaw at rest and with movement to ensure that she is ready to transition to solid foods. If needed, your baby's therapist will tailor a pre-feeding plan specific to your child's needs. A pre-feeding program will help your baby learn the necessary foundational feeding skills while gaining the muscle strength needed to ensure a safe transition to solid foods.

## Signs of feeding readiness

After a pre-feeding program is established with your child's feeding therapist, if necessary, what are other ways to know that your baby is ready for solids? The American Academy of Pediatrics and the World Health Organization recommend beginning solids at six months of age. For babies born before 36 weeks' gestation, their *adjusted age* is used until they are two years old. For example, if you have a 6-month-old baby who was born at 32 weeks, her adjusted age would be four months old, which for most babies is too early to begin solids. Additionally, due to motor delays and decreased muscle tone in babies with Down syndrome, it is sometimes better for them to be introduced to solids a little later than is recommended for a typically developing child, to make sure that they have the foundation needed for success.

Along with your baby's therapy team and healthcare provider, you can look at a variety of factors to determine if your child is ready to transition to solid foods. When your baby begins looking at or reaching for the foods that you or other family members are eating, that is a sign that she may be ready to start solids. Before moving to solid foods, you should make sure your baby is medically stable, and that she has the developmental skills to begin taking in solid foods. If your developmental team does not feel your baby is ready, it is okay to wait before introducing solids.

For your child to start self-feeding, she must have the following motor skills:

- Good head and neck control.
- Good trunk control and muscle strength.
- Stability in supported sitting with hips and knees at a 90-degree angle and feet grounded. She should be able to sit well in a high chair without falling over. Blankets or wedges can help support her if the chair is too big.
- The ability to get her hands to her mouth in a seated position.

Many feeding skills are dependent on gross motor skills. If your baby does not yet have these skills, it may be more difficult for her to hold food in her hands or use her tongue to move her food to the biting surfaces of her teeth and gums for chewing. If this is the case for your baby, she may need to begin with foods with a smoother texture, such as a soft solid like banana or avocado, until her oral motor skills become more refined. Working with a feeding therapist to modify BLW techniques as needed for your child will allow her to have many of the positive benefits of child-directed feeding, even if you are using a smoother texture.

## STRATEGIES FOR MOVING TO SOLID FOODS

As discussed in the previous section, if your baby has motor challenges, you can add a transitional step between breastfeeding and true baby-led weaning by starting with purees or mashed soft solids instead. For this transitional step, pick a food such as a stage 1 or 2 baby food (usually labeled as such on the packaging by the manufacturer), which is thin, smooth, or liquid-texture puree. You could also choose oatmeal cereal or mashed soft solids, such as banana, avocado, or cooked sweet or white potato. Your baby's feeding therapist, if she has one, can help you select foods that are easily digestible and that are an appropriate texture and shape for your baby's current feeding skill levels. It may take some time for your baby to tolerate the tastes of different foods and to be comfortable with soft, lumpy textures like oatmeal or cottage cheese. It is important to remember that it may require multiple exposures to new foods through seeing, touching, smelling, and observing others eat the food before your baby accepts it.

As you initially move from breast milk to solids, try using the following tools to help your baby learn to eat safely and effectively. Your baby with Down syndrome may need to start the transition to solid foods with a silicone feeder or a flat-bowled spoon. You can do this by simply handing the feeder or preloaded spoon to her and encouraging her to bring it to her mouth. Initially, your child's biggest challenge may be getting her hand to her mouth due to low tone and motor delay, and you may have to support her elbow to help her bring food to her mouth. Eventually, you can place the silicone feeder or preloaded spoon on the high chair tray or table for her to pick up herself, facilitating completely independent eating.



*NatureBond™ baby fruit feeder is an example of a silicon feeder recommended for transitioning babies with DS to solids if needed.*

- **Silicone feeders** – Silicone feeders have handles that give your child something easy to grasp so that the food doesn't slip out of her hand and frustrate her, which can sometimes happen with soft solids. Once your baby can hold the feeder at her mouth independently and gnaw it, she will be able to extract food, which will motivate her to continue trying. This gnawing also helps to increase jaw strength, and it immediately rewards her with food. Start with pureed foods like a stage 2 texture that she can remove easily from the silicone feeder.

Once she can do that, you can progress to soft solid foods such as avocado, banana, steamed butternut squash, sweet potato, or baked potato. Silicone feeders are better than net feeders, as they encourage biting and gnawing to get the food out. The net feeders make it too easy for a baby to suck the food out of them without using their gums to bite and chew. Be sure to fill the feeder to capacity so that when you gently squeeze it, you will see the food come immediately through the holes on the top. Your child may soon be going through several feeders very quickly in one sitting, as she gets better at removing the food. Some parents purchase a number of feeders and fill them up ahead of time, so they're ready with a full one as soon as the previous one is emptied. Once your baby can hold the feeder independently and keep it at her mouth, you can use the feeder less frequently and start to give her the whole food such as banana and avocado in strips, or small chunks or mashes on her tray. If your baby is sucking the feeder at midline or thrusting with her tongue, you may have to guide the feeder to the side of her mouth to encourage her to bite instead of suck on it.

- **Preloaded spoons** – Dip a flat-bowled spoon into a food that will stick to it, like mashed avocado, bananas, or potatoes. A flat-bowled spoon makes it easier for your baby to get the food off than other types of spoons.



After the transitional phase, or if your feeding team has determined that your baby does not need a transitional phase, we suggest that you start practicing with solids once a day and slowly increase to three meals and two snacks, with the goal that solid foods be the primary source of nutrition by the time your baby is a year old, adjusted as necessary if she was born prematurely. A fundamental step toward a successful transition to solid foods is including your baby in family meals right from the start. Sharing meals with your baby, even if she is only exploring smells and textures to start, allows you and other family members to model appropriate feeding behavior while exposing her to different foods. Dinnertime, when everyone is together, can be a great time to introduce that first daily meal of solid foods. Eating together as a family gives your baby an opportunity to watch and try to copy the eating practices of others and to enjoy their company, which can be very motivating for her.

As your baby's strength and self-feeding abilities improve, she will be able to grip and pull food with her teeth, use a munching pattern, move food from one side of her mouth to another with her tongue, and use a raking gesture to pick up foods. As she gains these skills, you can gradually expose her to foods that are more difficult to break down, such as pasta, mashed beans, chicken thigh pieces, soft ground meats like meatballs, and meltable solids. Your baby's feeding therapist can guide you in selecting food textures that are appropriate for your baby based on her feeding skills.

## GAGGING, COUGHING, AND CHOKING

Gagging and coughing are natural and protective responses that can happen as young babies learn to eat solid foods. They are signs that the baby is protecting her airway. They are not the same as choking and rarely require intervention. In fact, intervening when someone is coughing or gagging can actually increase the risk of choking, which is why it is essential that parents understand the difference. In contrast, **choking**, which is usually silent, indicates that the protective reflexes have been bypassed and can no longer function. Intervention is urgently required when someone is choking.

At birth, the triggers for the gag reflex are located far forward in the mouth, but they gradually move further back, closer to the airway, as babies become more experienced and proficient eaters. As adults, we only gag when food is near our airway. In contrast, due to the nature of a baby's gag reflex, they sometimes choke or gag even if food is not near their airway. As babies bite, gnaw, chew, and move food around in their mouths, their gag reflex becomes less exaggerated and more like the adult gag response. Your baby's oral exploration of toys can also help desensitize her gag reflex.

### Types and Textures of Foods

- **Purees** – Not typically used in BLW but babies with Down syndrome may need to start with purees as they are an easier texture to manage. Purees can range from thin to lumpy and include baby cereals like oatmeal, stage 1 and 2 baby foods, and table food smooth purees like hummus, or thin homemade smooth purees. You can offer these foods on a **pre-loaded spoon**, a spoon that you load with a small amount of food, and hand it in a vertical position to your baby with the handle side down. You may need to help her guide it to her mouth initially. When she is ready, you can also let her pick the spoon up from her high chair tray or the table so that she can guide it into her own mouth. You can also put purees in a silicone feeder.
- **Soft Solids** – These foods start in solid form but can be easily mashed and swallowed by most babies. Avocado, baked potato, baked sweet potato, or banana pieces are all examples of soft solids. Babies can finger feed these soft solid chunks or soft solids mashed with a fork on their tray. Food mashes (soft solid foods mashed with a fork) have some texture, and your baby can pick them up with her hands. Soft solids and food mashes can also be placed on a preloaded spoon or in a silicone feeder. Examples of mashes are avocado, banana, lumpy mashed potatoes, or hummus puree. They often stick well to a preloaded spoon.
- **Meltable Solids** – These foods break down when mixed with saliva and will dissolve in your baby's mouth. Examples are Bamba, Pirate Booty, Puffs, and Mum-Mums.
- **Solids** – These foods require chewing skills for breakdown and include toast, bagels, apples, chicken, hamburger, etc.
- **Mixed Textures** – These foods have a variety of textures together and require more complex chewing and oral motor skills. Soups and casseroles are examples of mixed textures.

# Gagging vs. Choking

## GAGGING



*Gagging is a safety mechanism that prevents babies from choking. Babies naturally have a more sensitive gag reflex than adults.*

**A gagging child will usually:**

- Have a wide-open mouth with the tongue thrust out
- Be *red* in the face
- Cough or sputter

**DO NOT INTERFERE WITH A CHILD WHO IS GAGGING.** Attempting to get food out of a child's mouth can move it further into the oral cavity, causing the child to choke.

## CHOKING



*Choking is a response to an obstruction in the upper airway and **it is an emergency.***

**A choking child will usually:**

- Be pale-faced and will begin to turn *blue*
- Have bluish lips
- Be unable to make any noise (may start to cough if there is only a partial blockage)

Choking is often **SILENT.**

**For any sign of choking, call 911 and perform first aid IMMEDIATELY. Learn more about first aid at [www.redcross.org](http://www.redcross.org).**

**Remember:**

**Loud and red, let them go ahead.  
Silent and blue, THEY NEED HELP FROM YOU!**

All caretakers should be trained in basic first aid including CPR and the Heimlich maneuver.

Many people worry that baby-led weaning is a risky way to transition to solids, especially for children with special needs. However, all babies are at risk of choking, regardless of how they are fed. For this reason, it is a good idea for all caregivers to be trained to perform the Heimlich Maneuver and Cardiopulmonary Resuscitation (CPR). Rather than being dangerous, a child-directed feeding approach, when done safely and with a qualified therapist, can have a profound positive impact on your baby and will enable her to be a safer and more proficient eater.

Some babies with sensory integration issues may have a stronger or more persistent gag reflex. Gagging can also occur more often in babies with a history of gastroesophageal reflux (GERD), prolonged nasogastric (NG) tube feeding, intubation, suctioning, or any other negative oral experience (see feeding tube chapter to learn more about oral aversions). Addressing these sensory issues is very important and should not be ignored. If your baby has these

issues, you may need to consult a feeding specialist who will work with you to desensitize your baby through food play and exploration before introducing solid foods. Pay attention to your baby's cues, especially if she is gagging for an extended period or showing extreme sensitivity to a particular food.

### Mom Tip

To help strengthen your baby's jaw and chewing, try playing oral tug-of-war. Place a thin washcloth on the inside of your baby's mouth, where her molars will come in, and pull gently as your baby resists by biting and pulling with her gums or teeth. This can also be done with Chewy Tubes® or other narrow teethers. This helps to assist in jaw strength and stability, which are foundational skills for chewing and eating. You can also use strips of food like a well-steamed broccoli tree or toasted bread strips.

## CHILD-DIRECTED FEEDING OVER TIME

By the time your baby is a year old developmentally, most experts would expect that she could self-feed a variety of foods, is weaned from drinking from a bottle, and will have solid food as her primary source of nutrition (instead of milk). She will eventually have the ability to hold strips of soft solid foods like ripened pear, or vegetables like steamed broccoli stalks and steamed asparagus. When your baby can pick up foods from the high chair tray, she

can self-feed mashes, meltable solids, and eventually, real solid foods such as chicken, meatballs, etc. Your baby's feeding therapist should be working on increasing jaw strength with biting and pulling of food strips, breaking down foods with munching and chewing, and eventually taking bites from whole and solid foods, like apples, sandwiches, and slices of pizza. Liquid transitions can go from breastfeeding to assisted straw drinking with a honey bear cup or plastic juice box, to

eventually moving to independent straw drinking and assisted open cup drinking using a small medicine cup. Your baby, if bottle-fed, may need to continue with bottle feeding past age one if she lacks foundational skills such as tongue and cheek retraction and lip rounding. If these foundational feeding skills are missing, she may not be able to take in enough volume and calories from food and cup drinking alone.

Child-directed feeding can have a long-lasting and therapeutic effect on babies with special needs. It can result in increased core strength, hand-to-mouth coordination, self-feeding, and independence, as well as improved oral motor and feeding skills. Because this approach can be life-changing for babies with Down syndrome, you might be tempted to try this on your own. However, it is crucial to have guidance and facilitation from trained professionals so your baby can safely transition to solid food feedings. A team approach with a feeding therapist, motor therapists, and a dietitian can help determine when your baby is ready to make the transition, help pick optimal seating, and ensure selection of developmentally appropriate food textures along the way. Skills acquired through child-directed feeding can help set a strong foundation for cognition, play, and speech development for the future. Even if your baby needs modifications to the original BLW recommendations in order to transition safely and effectively to solid foods, with repeated practice, she will become stronger and more capable, eventually following the baby-led weaning approach just like her typically-developing peers.



### Mom Tip

Your baby needs to explore food through taste, smell, and touch, and this can get quite messy. To minimize cleanup, consider feeding your baby in her diaper only or use a long-sleeved bib.



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Maura and Will

## When Breastfeeding Doesn't Go as Planned

KIMBERLY BARBAS, BSN, RN, IBCLC

Maybe you've always known that you would breastfeed your baby. Maybe you came to the idea by watching friends and family, reading and learning about the benefits, and wanting the best for your baby. Or maybe you had never given breastfeeding or breast milk a second thought—until there was a baby, a diagnosis, a medical complication, and the suggestion that breast milk was the healthiest choice for your newborn.

If breastfeeding is a priority for you, what do you do when it doesn't go as planned? Happily, there is more than one way to define breastfeeding. The image of blissfully feeding your baby at breast while the morning sun streams in the window can be your happy place, even if the reality is that you are sitting up alone in the dark of night with a breast pump while your baby recovers in the hospital, or gains strength and the ability to suck efficiently, or the ability to feed by mouth. It just means revising your goals a little bit.

Think of each milestone as an accomplishment, and a step toward your goal of providing breast milk for your baby: the first time your baby receives your colostrum, the first time you are able to pump an ounce of milk, the first time your baby is fed your breast milk by whatever method works for him. You are still a *breastfeeding mother* no matter how your baby receives your breast milk!

Your first goal is to establish and maintain an adequate milk supply to meet your baby's needs. Your next goal is to have your baby receive that breast milk, whether it is given by tube feeding, bottle feeding, teaspoon, or nursing supplementer—whatever method you and your baby's medical team decide is the most appropriate.

## Triple Feeding Tips

Triple feeding is the process of offering your baby your breast and allowing him to attempt to breast-feed, then supplementing him with pumped milk or formula, and finally pumping to ensure that you maintain an adequate milk supply.

- Limit yourself to short, frequent breastfeeding practice sessions of 10–15 minutes per breast. This will give your baby more chances to try the breast without getting too exhausted to finish the feeding, and will prevent you from spending hours trying to feed.
- Prepare your bottles ahead of time, so you have one ready to give right away after breastfeeding.
- If you have help, allow someone else to give your baby the bottle, while you use the breast pump.
- Use a hands-free pumping bra, and express your milk while you give your baby the bottle.
- Try to complete all feeding and pumping activity within 45 minutes to allow time to rest between feeds.
- If possible, purchase extra bottles, nipples, and pumping supplies, so you can wash everything together once or twice daily.

Throughout this process, you can continue to offer your breast to your baby. This counts as a victory even if your baby simply nestles in and licks and tastes your milk. Holding your baby skin-to-skin and trying recreational breastfeeding without pressure for your baby to take in a complete feeding are all steps toward your goals.

The process of teaching a baby to breastfeed often involves long rounds of practice at the breast, followed by bottles, then pumping, cleaning everything, and starting all over again. This is known as *triple feeding*, and it can quickly become exhausting and stressful, which in turn can affect your milk supply! If this vicious cycle is interfering with the time you spend enjoying your baby or is affecting how you feel about yourself as a mother, then it is time to take a step back. Consider the following:

- Take a break from the triple feeding routine, and perhaps just bottle feed for a feeding or two, or for an entire day.
- Spend time holding your baby skin-to-skin as much as you can, without any pressure to feed at the breast.
- Enlist family or friends to help with some of the feedings, or to take you out for a diversion.
- After you have an established milk supply, around 3 to 4 weeks, cut back to pumping 4 to 6 times a day and find a reasonable schedule that allows you to maintain your breast milk output. Considering pumping a little more frequently during the day so that you can take a 5-hour stretch to sleep at night.

- Set short-term goals. Tell yourself, “I can do this for one more day, the weekend, a week, two weeks,” or whatever amount of time seems reasonable to you. Reevaluate how you feel at the end of each time frame and renew your commitment if you are able. Consider setting a reward for yourself at the end of each small goal.

## ADDITIONAL WAYS TO FEEL CLOSE TO YOUR BABY

While working on your breastfeeding relationship, you may desire other ways to bond with your baby. Try some of the following ideas:

- **Infant massage** – this can be a special time where you use lotion or oil to relax your baby with your gentle touch before sleep.
- **Reading or singing to baby while feeding him** – your voice is soothing to your baby, and you can develop special songs that are meaningful to you and your baby.
- **Cuddle during feeding** – you can snuggle your baby during almost any alternative feeding method. Enjoy those precious moments of smelling your baby’s downy hair and rubbing his tiny fingers.
- **Making eye contact** – gaze at your baby and chat with him about the day to engage him during feeding.
- **Skin-to-skin contact** – lay your baby, clad only in a diaper (and possibly a hat) against your bare chest. Wrap a blanket over you both and relax.
- **Minimize distractions** – Turn off electronic devices and the television during feeding to eliminate distractions.

When breastfeeding doesn’t go as planned, you may have feelings of loss and sadness—you are grieving the loss of a breastfeeding relationship you had looked forward to. This is very common among mothers, and you need to give yourself permission to feel sad and work through this grief. Parenting is full of expectations, goals, and dreams for our children—and the reality that not all of them will be fulfilled can be hard to accept. Even if your baby does not latch, is unable to breastfeed directly, or you are unable to produce enough milk, you must give yourself credit for the efforts you have made to achieve this goal for your child. Any amount of breast milk or breastfeeding is an accomplishment. It is not an easy task, but providing your baby with your milk, for however long your breastfeeding journey lasts, should give you the satisfaction and the comfort of knowing that you’ve done the best for your baby.

## Mom Story

### LINNEA & ELLIOTT



My son, Elliott, who is now 3½ years old, never did successfully breastfeed. I nursed my first child for 25 months and never thought I wouldn't nurse Elliott as well. He was in the NICU for 22 days, and I think it didn't help that I couldn't hold him as much as needed. I had pneumonia when I went into labor with him and was so tired during the first few days that it didn't bother me that he wasn't nursing.

Every time I would try to latch him, he would scream and fight me. It was heartbreaking and frustrating, and I felt like a failure. I ended up exclusively pumping for ten months, attempting to latch him at least once per day for the first five months.

I was overwhelmed with guilt and was angry that I had to pump. The pump took over our lives, and I plummeted into postpartum depression and postpartum anxiety and I felt as if I couldn't comfort either of my two children because

I was always connected to the pump. I didn't respond well to a pump but had a hospital-grade pump, which was the only one that would work. I struggled to make enough milk and had to fortify and supplement with formula. I was determined to get Elliott to nurse, and when that didn't happen, I was determined to give him a year of breast milk. I figured I should at least give him that precious gift. I got to ten months and was literally on the edge of a nervous breakdown. I had to stop for my sanity, and for my children.

*LINNEA & ELLIOTT (CONTINUED)*

I now have a third child, and he breastfeeds exclusively. He is 14 months old and going strong. The first six weeks were excruciating, and I almost gave up. But we worked past it. I have not touched a pump since I stopped pumping for Elliott, and I actually feel that I have an aversion to them, almost like post-traumatic stress disorder. There is so much freedom in exclusively breastfeeding, and I do not take it for granted with this child after what I went through with Elliott.

I'm sad that Elliott and I never got to have the nursing bond; however, we are very bonded. I have a whole new perspective, too. I no longer judge moms for feeding their babies however they need to. Pumping was the hardest thing I've ever done (next to labor), and I wouldn't wish it on anyone. I literally spent about 35 hours a week pumping, and then another 35 hours a week bottle feeding. Not to mention washing all the parts!

My first born was left with very little of my time, and she suffered for it. Every drop of milk was precious to me, and I never wasted any of it, but it became an obsession and a burden. I'm so grateful that I got another chance to nurse a baby, as I feel it has helped me to heal emotionally and close the wounds from the struggle I had with Elliott.

On a final note: One day I was nursing my youngest and Elliott was watching curiously. He came up to me and asked for milk, and I said, "Okay, you want to try?" He nodded his head yes, and I cradled him in the nursing position. I braced as he latched on, assuming he would bite me as he had never nursed and didn't know how. To my surprise, he latched on and took three or four big swallows of milk and then pulled off and said, "Yummy!" He tried once more and then got a little rough, so we stopped. He seemed happy that he got to try it, and I know I smiled from ear to ear. My heart felt so full of joy as I looked into his big blue eyes while he successfully nursed for all of 30 seconds. It was a special moment indeed. He hasn't asked again, but I think he needed that moment as much as I did.



## Mom Story

### MAURA & WILL



I always knew that when I had children, I would breastfeed. I come from a family of formula-fed babies, but some of my close friends breastfed their children. I watched their journeys and longed for the bond they had with their babies. Some of them struggled initially, but they all eventually succeeded.

When I found out at 12 weeks pregnant that our baby had Down syndrome, I began researching everything I could. I learned that it is sometimes difficult for babies with DS to breastfeed, so I scoured the internet looking for advice or stories about people who had successfully breastfed, but came up with very little.

I attended a breastfeeding class at about 30 weeks that was very informative. The lactation counselor talked about the benefits of breastfeeding, positions, and support. At the end of the class, I sheepishly approached her and told her that my baby had Down syndrome. She was very kind but had little advice to offer. She said the only thing she knew was that sometimes these babies need their milk thickened.

William was born at 37 weeks via emergency c-section. He spent three days in the NICU where he was given formula because my milk had not come in. I had had a traumatic birth experience, developed an infection, and became septic. Despite all that, I pumped every three hours around the clock, praying my milk would come in. I was only able to produce about 10 milliliters of colostrum at each pumping session, but I kept at it. The day Will was released from the NICU, I finally pumped 30 milliliters of breast milk. It felt like such a victory! I worked with a lactation consultant while in the hospital, trying to get Will to latch. The only way he would successfully latch was with a nipple shield. Will was exclusively breastfeeding just days after coming home from the hospital with the goal to eliminate the nipple shield.

Shortly after birth, Will was diagnosed with an atrial septal defect and a ventricular septal defect. We were told that he would most likely need open-heart surgery to repair the holes. We were advised to keep an eye on his breathing and weight gain. During the first three weeks Will was home, he was breastfeeding and gaining weight without issue. Just after he turned three weeks old, however, he started to go into heart failure and began losing weight. He was put on

*MAURA & WILL (CONTINUED)*

Lasix, a diuretic, to manage his heart failure. After discussing our options with Will's cardiologist and nutritionist, I decided it would be best for Will if I pumped and added formula to his breast milk to increase the calories. I was heartbroken, but it felt like the right decision for the health of my baby.

It was such a stressful time. I was learning the ins and outs of being a mom, had a baby in heart failure, and was dealing with postpartum depression and anxiety. I was concerned that Will would lose the skill of nursing that we had worked so hard to establish. I was so proud of what we had accomplished, and it felt as if it was taken away from us. Nothing was as I had dreamed it would be. The bond that I longed for was clouded with stress, anxiety, depression, and fear.

Three days after I stopped nursing, I learned about a supplemental nurser from someone on social media. I called the lactation consultant at our local hospital and made an appointment to try out the SNS together. I have heard of others having great success with this system, but it just did not work for us. In three short days, Will had become accustomed to drinking from a bottle. It was awkward and stressful for me to use a SNS, so after a few attempts, I made the choice to pump exclusively. I held out hope that maybe after Will's heart repair, we could try to nurse again. He slowly gained weight and grew while waiting for his heart repair, which happened when he was three months old.

Despite my best efforts, I was never able to establish a sufficient supply of breast milk. I pumped every two to three hours, took fenugreek, ate oatmeal, and any other foods that anyone suggested would increase my supply. I would have eaten dirt if it increased my supply! I was also power pumping once a day. On Christmas Eve, a friend brought me a little package with some lactation cookies and an essential oil blend that was supposed to increase my supply. My Christmas morning pump produced five ounces of breast milk. It felt like a Christmas miracle!

Will was taking only an ounce of breast milk at each feeding, so I was able to keep up with his demand, even with my low supply. At times pumping felt like a daunting task, but I was grateful that I could provide for Will in that way. Some days I wanted to give up, but I had the goal to try to nurse again after heart surgery. We did try after surgery as soon as Will was out of the cardiac ICU. He latched once in the hospital, but I was cautioned by the cardiac team not to spend too much time trying to breastfeed while he was still recovering. We tried again when we got home from the hospital, but Will got upset each time. The boy wanted his milk, and fast!

I continued to pump for two more months, but Will's demand was far more than I could keep up with. We mixed breast milk with formula to provide adequate volume. As soon as we began adding more formula than breast milk, I decided it was time for me to stop pumping. This was a difficult decision, but it was the best one for Will and me. My breastfeeding journey was not what I had imagined it would be, but I was able to provide my son with breast milk for five months, and I am very proud of that.



# Epilogue

Before I had my baby with Down syndrome—my first child—I always assumed I would breastfeed all my children. I watched my sister have successful breastfeeding experiences with both of her babies; I knew the health and bonding benefits, and I knew I wanted that for my children. In my mind, that was what good mothers did. And when my son was born with Down syndrome, I was even more determined when I heard about the benefits of breastfeeding for improving IQ and oral muscle tone.

Unfortunately, we ended up having a perfect storm of issues between his weak suck, my low milk supply due to insufficient glandular tissue (IGT), my inexperience as a first-time mom, and my overwhelming postpartum depression (PPD).

When I was trying to breastfeed my son, I struggled with profound worry over health concerns when he came home after spending his first couple of weeks in the NICU. I obsessively kept notes about how much he ate from me, how much he took by bottle, and how many wet diapers he had, just like they did in the hospital. I was also taking Reglan®, which I later found can be a depressant, to increase my milk supply. My PPD was mounting each day.

The lactation consultant at the time also told me to hold my baby for feeding only when I was trying to nurse him with the supplemental nurser. The idea was that he would be motivated to nurse so that he could be close to me. During that time, my mother-in-law, sister, and husband did the bottle feedings with my pumped breast milk, which was supplemented with formula. Because the SNS kit and nipple shield were so frustrating, and because I was sad that he wasn't able to nurse at the breast as I had envisioned, every feeding felt like a negative experience. With PPD, my perceived negative feeding experiences started to impact bonding with my baby.



*Stephanie Meredith and Andy. Stephanie Meredith is the co-author of Welcoming a Newborn with Down Syndrome: A New Parent's Guide to the First Month, and several other books.*

After 3-4 weeks, I went to see a therapist about my PPD where he told me to throw away my notes as long as the baby was gaining weight and thriving, and he gave me coping strategies for depression like getting out of the house for a walk each day and inviting trusted people to visit in the early evening when my PPD was most acute. I also needed to stop taking the Reglan®—which was a double-edged sword because it removed a depressant from my system but also lowered my milk supply. He also advised me to take turns bottle feeding my baby to improve our bonding.

Ultimately, I ended up pumping breast milk for my baby until I went back to work when he was eight weeks old. I didn't pump long term because pumping felt like a reminder of my failure. I know that was a result of my PPD and I know that's not true now, but it felt like that under the cloud of PPD. At the time, the bottle feeding felt more peaceful because I could just snuggle him and wasn't overcome with my worry about whether he was getting enough milk from me. Looking back, I believe I could have had a successful supplemental breastfeeding experience with a better state of mind and the wonderful preparation and advice in this book, but I just couldn't overcome the weight of the PPD at that time while also coping with breastfeeding challenges.

I used other strategies to bond with my son, like infant massage and snuggling and reading to him during bottle-feedings. This wasn't the ideal scenario I had envisioned, but it ended up being the solution I needed for my mental health under our unique constellation of circumstances. This was my first hard lesson in learning that as moms, we sometimes aren't able to live up to our own expectations about being a "good mother," but things can still turn out just fine. Nineteen years later, I still feel pangs of sadness about my struggles with breastfeeding, but my son has grown into a healthy, happy, and thriving man with Down syndrome, and I am profoundly proud of him ... and even of myself as his perfectly imperfect mom.

# Biographies

**KIMBERLY BARBAS, BSN, RN, IBCLC** is a lactation consultant and pediatric nurse with over 30 years of experience working with families. Kim established the Lactation Support Program at Boston Children's Hospital in 1998. She has dedicated her expertise to changing the culture around human milk use in the pediatric inpatient setting through education, evidence-based practice, and innovative programs. She is known locally and nationally as a lactation educator, presenting at conferences focusing on breastfeeding the medically complex infant. Her research interests include infants with congenital heart disease and management of chylothorax for the breast-milk-fed infant.

**KATHLEEN CARR, DNP, RN, CPNP** completed her undergraduate and graduate nursing education at Boston College, and her doctorate at the University of Massachusetts, Boston. After graduation from her primary nursing program, Kathleen worked as an inpatient staff nurse in the Cardiovascular Program at Boston Children's Hospital. During this time, she also completed her Masters of Science in Nursing. Upon graduation from her nurse practitioner program, Kathleen took a position at Wareham Pediatrics in Wareham, Massachusetts where she worked for the next seven years providing primary care to infants, children, and young adults. Kathleen returned to Boston Children's Hospital in 2014 to take a position as a nurse practitioner in the Growth and Nutrition Program. In this role, Kathleen provides care for infants and young children with feeding difficulties and failure to thrive. She completed her Doctorate of Nursing Practice degree in 2017, and her doctoral capstone project was titled "An Initiative to Improve Parental Knowledge and Competency for Pediatric Patients with Nasogastric Tubes." Kathleen was recognized by the Boston Globe's "Salute to Nurses" in May 2018.

**ELLA GRAY CULLEN, RN, CLC** is a Registered Nurse, Certified Lactation Counselor, and a trained doula. She is the mother of a daughter with Down syndrome and the founder and executive director of Julia's Way, a 501(c)(3), nonprofit organization dedicated to reimagining life with Down syndrome. She developed her passion for helping women breastfeed while working as a nurse internationally with Doctors Without Borders. She now brings that experience and passion to supporting and encouraging women who want to breastfeed their babies with Down syndrome.

**KATHRYN DAVIDSON, MS, CCC-SLP, BCS-S** is a speech-language pathologist and board-certified specialist in swallowing disorders. She completed her undergraduate and graduate training at Boston University and a post-graduate clinical fellowship at Boston Children's Hospital. Her clinical responsibilities include diagnosis and management of pediatric feeding and swallowing disorders. She has advanced training in both clinical and instrumental assessments, including modified barium swallow studies and fiberoptic endoscopic evaluations of swallowing. Katie has a special interest in facilitating safe oral feeding in infants and children with medically complex conditions and supporting the family throughout the process.

**EMILY JEAN DAVIDSON, MD, MPH, RYT** is an attending physician in the Complex Care Service and in the Down Syndrome Program at Boston Children's Hospital where she also serves as the director of prenatal services, caring for families who have received a prenatal diagnosis of Down Syndrome. Dr. Davidson is an assistant professor of pediatrics at Harvard Medical School and also a registered yoga teacher. She received her undergraduate degree from Harvard/Radcliffe College, her medical degree from Yale University School of Medicine, and her Masters of Public Health from Harvard. She completed her residency in Pediatrics and fellowship in Developmental-Behavioral Pediatrics at Boston Children's Hospital.

**KAYLA HERNANDEZ, MS, CCC-SLP, BCS-S** is a pediatric speech-language pathologist in the Feeding and Swallowing Program at Boston Children's Hospital. Kayla completed her undergraduate and graduate education at Boston University, and her clinical fellowship at Boston Children's Hospital. She specializes in the evaluation and treatment of pediatric feeding and swallowing disorders and has a special interest in clinical and instrumental dysphagia assessment in neonates, infants, and medically complex children. She is a board certified specialist in swallowing and swallowing disorders.

**RACHELLE LESSEN, MS, RD, IBCLC, LDN** is an International Board Certified Lactation Consultant and has a Master of Science degree in health education. She is an adjunct professor at Drexel University teaching Clinical Issues in Human Lactation and Introduction to Human Lactation. She was one of the creators of the Pathway 2 Lactation Program at Drexel. In her role as a lactation consultant at the Children's Hospital of Philadelphia, Rachelle provides lactation consults for families of patients admitted to the hospital and assists mothers and babies with breastfeeding. She counsels families in the Fetal Heart Program prenatally to offer support and guidance related to breastfeeding an infant with congenital heart disease. She is currently conducting research on breastfeeding infants after neonatal cardiac surgery. She also has an outpatient clinic to help mothers with breastfeeding challenges. She specializes in nutrition-related problems, including food allergies and poor growth. Rachelle is the author of the chapter "Expressed Human Milk Preparation and Handling" in the publication *Guidelines for Preparation of Human Milk and Formula in Health Care Facilities, Third Edition* and is the co-author of the International Lactation Consultant Association (ILCA) publication "Risks of Not Breastfeeding" and the Academy of Nutrition and Dietetics (AND) Position Statement on Breastfeeding. She has written chapters or articles for various publication on issues related to breastfeeding and nutrition.

**HEATHER MILLER** is a community educator with the Australian Breastfeeding Association (ABA). Along with her work in breastfeeding education, she has a particular interest in breastfeeding and Down syndrome since her son, Austin was born with Down syndrome in 2014. Her current role is in developmental disability health education for people with an intellectual disability, medical undergraduate teaching, and health professionals. Heather also works at ABA's National Office developing professional development resources for breastfeeding counselors and community educators.

**JILL RABIN, MS, CCC-SLP/L IBCLC** is a pediatric speech pathologist and International Board Certified Lactation Consultant who works with the 0 to 3 population. She combines both of her professions in assisting at-risk babies and babies with special needs in transitioning to breastfeeding. Her areas of expertise include working with young babies with feeding aversion, complex breastfeeding cases, and transitioning selective eaters to solid foods. She has lectured nationally and internationally on the benefits of breastfeeding babies with special needs and the use of baby-led weaning in babies with Down syndrome.

**JENNY THOMAS, MD, MPH, IBCLC** is a pediatrician and breastfeeding medicine specialist at Aurora Healthcare in Franklin, Wisconsin and is a clinical assistant professor of community and family medicine and pediatrics at the Medical College of Wisconsin. She has been an International Board Certified Lactation Consultant since 2003. She is now serving on the American Academy of Pediatrics Section on Breastfeeding Executive Board after spending several years as the chief of the Chapter Breastfeeding Coordinators. She is the author of *Dr. Jen's Guide to Breastfeeding* and the "Academy of Breastfeeding Medicine. Clinical Protocol #16: Breastfeeding the Hypotonic Infant."

**MARSHA WALKER, RN, IBCLC** is a registered nurse and International Board Certified Lactation Consultant. She has been assisting breastfeeding families in hospital, clinic, and home settings since 1976. Marsha is the executive director of the National Alliance for Breastfeeding Advocacy (NABA). She served the International Lactation Consultant Association (ILCA) as vice president (1990-1994) and president (1999). She is a previous board member of the US Lactation Consultant Association, Baby Friendly USA, and the Massachusetts Breastfeeding Coalition. She serves as USLCA's representative to the USDA's Breastfeeding Promotion Consortium, NABA's research, education, and legal branch's representative to the US Breastfeeding Committee, associate editor of *Clinical Lactation*, and a board member of the Massachusetts Lactation Consultant Association. Marsha is an international speaker, and an author of numerous publications including ones on the hazards of infant formula use, and *Breastfeeding Management for the Clinician: Using the Evidence, 4th edition*.

**JEANETTE ZAICHKIN, RN, MN, NNP-BC** has been a neonatal nurse since 1978. She has experience in small community hospitals and major medical centers in various roles, including bedside nurse, clinical nurse specialist, and manager. Jeanette has served as a consultant to the American Academy of Pediatrics Neonatal Resuscitation Program (NRP) Steering Committee since 1998 and currently serves as editor of the NRP *Instructor Toolkit* and associate editor of the *Textbook of Neonatal Resuscitation*. Jeanette is also the editor of a book for parents, titled *Understanding the NICU*. Jeanette leads Positive Pressure, LLC, a business enterprise that provides instruction, consultation, and program development for healthcare professionals who practice and teach neonatal resuscitation.





# Resources

## Breastfeeding support

- **Julia's Way** is dedicated to re-imagining life with Down syndrome with a specific focus on supporting mothers who want to breastfeed their babies with Down Syndrome. [www.juliasway.org](http://www.juliasway.org)

## Breast reduction surgery

- ***Defining Your Own Success: Breastfeeding After Breast Reduction Surgery*** by Diana West, BA, IBCLC. [www.bfar.org/book.shtml](http://www.bfar.org/book.shtml)

## Child-directed feeding

- ***Baby-led Weaning: The fuss-free way to introduce solid foods*** by Gil Rapley [www.rapleyweaning.com](http://www.rapleyweaning.com)
- **The Ellyn Satter Institute** has as its mission to transform lives by furthering Ellyn Satter's models for positive and joyful eating and feeding. [www.ellynsatterinstitute.org](http://www.ellynsatterinstitute.org)
- **Wholesome Baby Food** provides information and recipes for making your own baby food. [www.wholesomebabyfood.momtastic.com](http://www.wholesomebabyfood.momtastic.com)
- **Feeding littles** focuses on Baby-Led Weaning and is run by an Occupational Therapist and a Registered Dietician. [www.feedinglittles.com](http://www.feedinglittles.com)

## Choking

- **Kids Health** provides clear and comprehensive information on choking. [www.kidshealth.org/en/parents/choking.html](http://www.kidshealth.org/en/parents/choking.html)

## Cleft palate support and information

- **The Cleft Palate Association** is working to advance patient care and research in individuals affected with cleft lip, cleft palate and other craniofacial anomalies. [www.acpa-cpf.org](http://www.acpa-cpf.org)
- **The Australian Breastfeeding Association** provides information on breastfeeding a baby with a cleft lip and/or palate. [www.breastfeeding.asn.au/bfinfo/cleftpalate](http://www.breastfeeding.asn.au/bfinfo/cleftpalate)
- **Cleft Lip & Palate Association** also provides information on breastfeeding a baby with breastfeeding a cleft lip and/or cleft palate. [www.clapa.com/treatment/feeding/breastfeeding](http://www.clapa.com/treatment/feeding/breastfeeding)

## Congenital heart disease

- **The Children's Heart Foundation** seeks to fund the most promising research to advance the diagnosis, treatment, and prevention of CHD. [www.childrensheartfoundation.org](http://www.childrensheartfoundation.org)
- **Little Hearts** is a national organization providing support, education, resources, networking, and hope to families affected by congenital heart defects. [www.littlehearts.org](http://www.littlehearts.org)

## Down syndrome organizations

- **Down Syndrome Diagnosis Network** connects and supports families with a Down syndrome diagnosis. They have Facebook groups for new and expectant parents as well as a yearly conference. [www.dsdiagnosisnetwork.org](http://www.dsdiagnosisnetwork.org)
- **Down Syndrome Pregnancy** provides books and other resources for those preparing for the birth of a child with Down syndrome, including a book for family members who may have questions. [www.downsyndromepregnancy.org](http://www.downsyndromepregnancy.org)
- **National Down Syndrome Congress** promotes the interests of people with Down syndrome and their families through advocacy, public awareness, and information. Use their affiliate program link to find an organization near you. [www.ndscenter.org](http://www.ndscenter.org)
- **National Down Syndrome Society** envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities. Use their local support link to find an organization near you. [www.ndss.org](http://www.ndss.org)

## Family & friends

- ***Your Loved One is Having a Baby with Down Syndrome*** by Nancy McCrea Iannone, Stephanie Meredith, and Amy Geoffroy. [www.downsyndromepregnancy.org/book/your-loved-one](http://www.downsyndromepregnancy.org/book/your-loved-one)
- Websites keeping family and friends updated
  - **Caring Bridge** [www.caringbridge.org](http://www.caringbridge.org)
  - **Post Hope** [www.posthope.org](http://www.posthope.org)

## Finding a lactation consultant

- **La Leche League** is a nonprofit organization that organizes advocacy, education, and training related to breastfeeding. Use their locator section to find a La Leche Group near you. [www.lllusa.org](http://www.lllusa.org)
- **US Lactation Consultant Association** Use their locator to find an International Board Certified Lactation Consultant in your area. [www.uslca.org/resources/find-an-ibclc](http://www.uslca.org/resources/find-an-ibclc)

## Foker process

- For more information about the Foker process visit [www.childrenshospital.org/conditions-and-treatments/treatments/foker-process](http://www.childrenshospital.org/conditions-and-treatments/treatments/foker-process)

## Growth charts

- **Centers for Disease Control** provides the latest growth charts for babies with Down syndrome. [www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html](http://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html)

## Milk bank information

- **Human Milk Banking Association of North America** [www.hmbana.org](http://www.hmbana.org)
- **Medolac** [www.medolac.com](http://www.medolac.com)
- **Ni-Q** [www.ni-q.com](http://www.ni-q.com)
- **Prolacta Bioscience** [www.prolacta.com](http://www.prolacta.com)

## Newborn screen

- Information about the newborn screen
  - [www.kidshealth.org/en/parents/newborn-screening-tests.html](http://www.kidshealth.org/en/parents/newborn-screening-tests.html)
  - [www.ghr.nlm.nih.gov/primer/newbornscreening/nbs](http://www.ghr.nlm.nih.gov/primer/newbornscreening/nbs)

## NICU

- **Hand to Hold** provides support, resources, and programs for NICU parents and family members before, during, and after the NICU experience. [www.handtohold.org/about](http://www.handtohold.org/about)
- ***Understanding the NICU: What Parents of Premies and Other Hospitalized Newborns Need to Know*** by Jeanette Zaichkin, Editor in Chief. <https://shop.aap.org/understanding-the-nicu-paperback> or available on Amazon.

## Prematurity

- **Family Advocacy Network** collaborates with the Preemie Parent Alliance to produce a quarterly webinar series on topics of interest to families of preemies and their providers. [www.nationalperinatal.org/fan](http://www.nationalperinatal.org/fan)
- **National Coalition for Infant Health** educates and advocates on behalf of premature infants from birth to age two. [www.infanthealth.org](http://www.infanthealth.org)
- **Preemie Parent Alliance** is a network of organizations offering support to families of premature infants. [www.preemieparentalliance.org](http://www.preemieparentalliance.org)
- ***Preemies: The essential guide for parents of premature babies*** by Dana Wechsler Linden and Emma Trenti Paroli

## Pumping

- **Kelly Mom** has a guide to exclusive pumping. [www.kellymom.com/mother2mother/exclusive-pumping](http://www.kellymom.com/mother2mother/exclusive-pumping)
- **Mom's Pump Here** helps you locate nursing rooms, lactation lounges, nursing pods, and breastfeeding friendly places to express milk or breastfeed. [www.momspumphere.com](http://www.momspumphere.com)

## Tube feeding

- **Feeding Matters** unites families, healthcare professionals, and the broader community to improve the care for children with pediatric feeding disorders. [www.feedingmatters.org](http://www.feedingmatters.org)
- **Feeding Tube Awareness Foundation** supports parents of children who are tube fed, while raising awareness of tube feeding as a lifesaving medical intervention. [www.feedingtubeawareness.org](http://www.feedingtubeawareness.org)
- **Oley Foundation** strives to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking. [www.oley.org](http://www.oley.org)

## Welcome a newborn with Down syndrome

- ***Welcoming a Newborn with Down Syndrome: A New Parent's Guide to the First Month*** by Nancy McCrea Iannone and Stephanie Hall Meredith. [www.downsyndromepregnancy.org/book/welcoming-a-newborn-with-down-syndrome](http://www.downsyndromepregnancy.org/book/welcoming-a-newborn-with-down-syndrome)
- Organizations that provide welcome baskets for new babies with Down syndrome
  - **Jack's baskets** [www.jacksbasket.org](http://www.jacksbasket.org)
  - **Brittney's Baskets of Hope** [www.brittanybasketsofhope.org](http://www.brittanybasketsofhope.org)



# How to Keep Your Breast Pump Kit Clean

Providing breast milk is one of the best things you can do for your baby's health and development. Pumping your milk is one way to provide breast milk to your baby. Keeping the parts of your pump clean is critical, because germs can grow quickly in breast milk or breast milk residue that remains on pump parts. Following these steps can help prevent contamination and protect your baby from infection. If your baby was born prematurely or has other health concerns, your baby's health care providers may have more recommendations for pumping breast milk safely.



## BEFORE EVERY USE

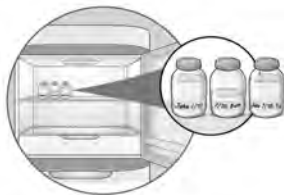


**Wash hands** with soap and water.

**Inspect and assemble** clean pump kit. If your tubing is moldy, discard and replace immediately.

**Clean** pump dials, power switch, and countertop with disinfectant wipes, especially if using a shared pump.

## AFTER EVERY USE



**Store milk safely.** Cap milk collection bottle or seal milk collection bag, label with date and time, and immediately place in a refrigerator, freezer, or cooler bag with ice packs.

**Clean pumping area,** especially if using a shared pump. Clean the dials, power switch, and countertop with disinfectant wipes.

**Take apart** breast pump tubing and separate all parts that come in contact with breast/breast milk.

**Rinse** breast pump parts that come into contact with breast/breast milk by holding under running water to remove remaining milk. Do not place parts in sink to rinse.

**Clean pump parts** that come into contact with breast/breast milk as soon as possible after pumping. You can clean your pump parts **in a dishwasher** or **by hand** in a wash basin used only for cleaning the pump kit and infant feeding items.

Follow the cleaning steps given on the next page.



# Clean Pump Kit

## CLEAN BY HAND



**Place pump parts in a clean wash basin** used only for infant feeding items. **Do not place pump parts directly in the sink!**

**Add soap and hot water** to basin.

**Scrub** items using a clean brush used only for infant feeding items.

**Rinse** by holding items under running water, or by submerging in fresh water in a separate basin.

**Air-dry thoroughly.** Place pump parts, wash basin, and bottle brush on a clean, unused dish towel or paper towel in an area protected from dirt and dust. Do not use a dish towel to rub or pat items dry!

**Clean wash basin and bottle brush.** Rinse them well and allow them to air-dry after each use. Wash them by hand or in a dishwasher at least every few days.

## OR CLEAN IN DISHWASHER

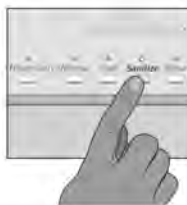


**Clean pump parts in a dishwasher,** if they are dishwasher-safe. Be sure to place small items into a closed-top basket or mesh laundry bag. Add soap and, if possible, **run the dishwasher using hot water and a heated drying cycle (or sanitizing setting).**

**Remove from dishwasher** with clean hands. If items are not completely dry, place items on a clean, unused dish towel or paper towel to air-dry thoroughly before storing. Do not use a dish towel to rub or pat items dry!

# After Cleaning

## FOR EXTRA PROTECTION, SANITIZE



**For extra germ removal, sanitize** pump parts, wash basin, and bottle brush **at least once daily** after they have been cleaned. Items can be sanitized using steam, boiling water, or a dishwasher with a sanitize setting. Sanitizing is especially important if your baby is less than 3 months old, was born prematurely, or has a weakened immune system due to illness or medical treatment.

For detailed instructions on sanitizing your pump parts, visit [www.cdc.gov/healthywater/hygiene/healthychildcare/infantfeeding.html](http://www.cdc.gov/healthywater/hygiene/healthychildcare/infantfeeding.html)

## STORE SAFELY



**Store dry items safely until needed.** Ensure the clean pump parts, bottle brushes, and wash basins have air-dried thoroughly before storing. Items must be completely dry to help prevent germs and mold from growing. Store dry items in a clean, protected area.

Learn more about safe and healthy diapering and infant feeding habits at [www.cdc.gov/healthywater/hygiene/healthychildcare](http://www.cdc.gov/healthywater/hygiene/healthychildcare).



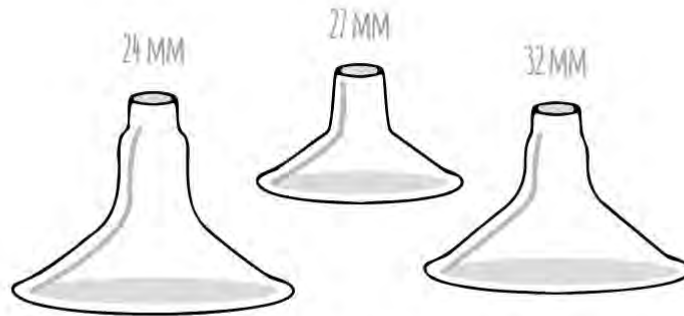
# FINDING THE RIGHT FLANGE SIZE

You've found your perfect pump, and now it's time to make sure you have all the right supplies. When it comes to Flanges (or breast shields), fit does matter, so use the guidelines below to get the most out of your breastfeeding experience.

## DETERMINE YOUR FIT

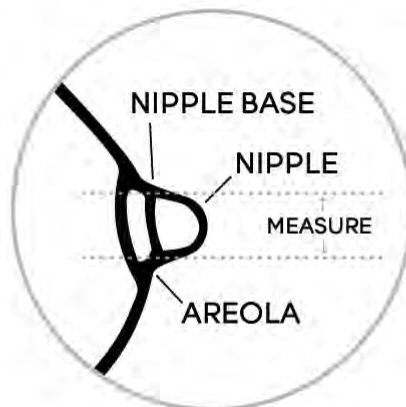
Flanges come in a variety of sizes, so knowing your fit is important for maximum comfort and pumping efficiency. The guide below is the first step in determining what's right for you.

### STANDARD BREAST PUMP FLANGE SIZES

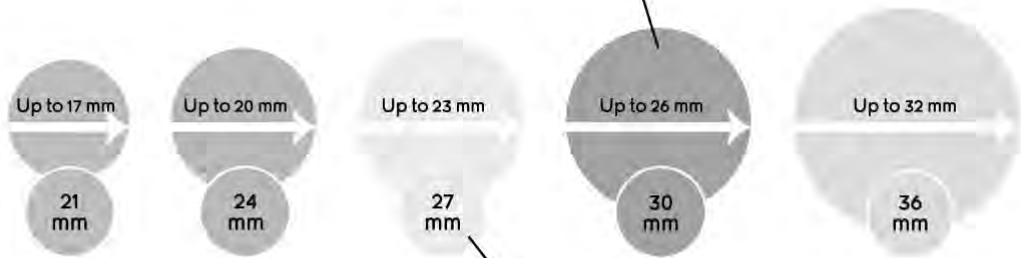


These are the most common flange sizes. Size can vary by breast pump manufacturer.

### WHAT TO MEASURE - The Diameter of Your Nipple



## Your Nipple Diameter Measurement



The PersonalFit  
Breastshield Size  
Recommended For You



During pumping your nipple is able to move freely in the breast pump flange tunnel. You will have space around your nipple and not much of the areola is drawn into the tunnel with the nipple.



During pumping some, or your entire nipple rubs against the sides of the breast pump flange tunnel.



During pumping more of your areola is drawn into the breast pump flange with your nipple. You may experience your areola rubbing up against the side of the breast pump flange funnel.

## TAKE THE COMFY TEST

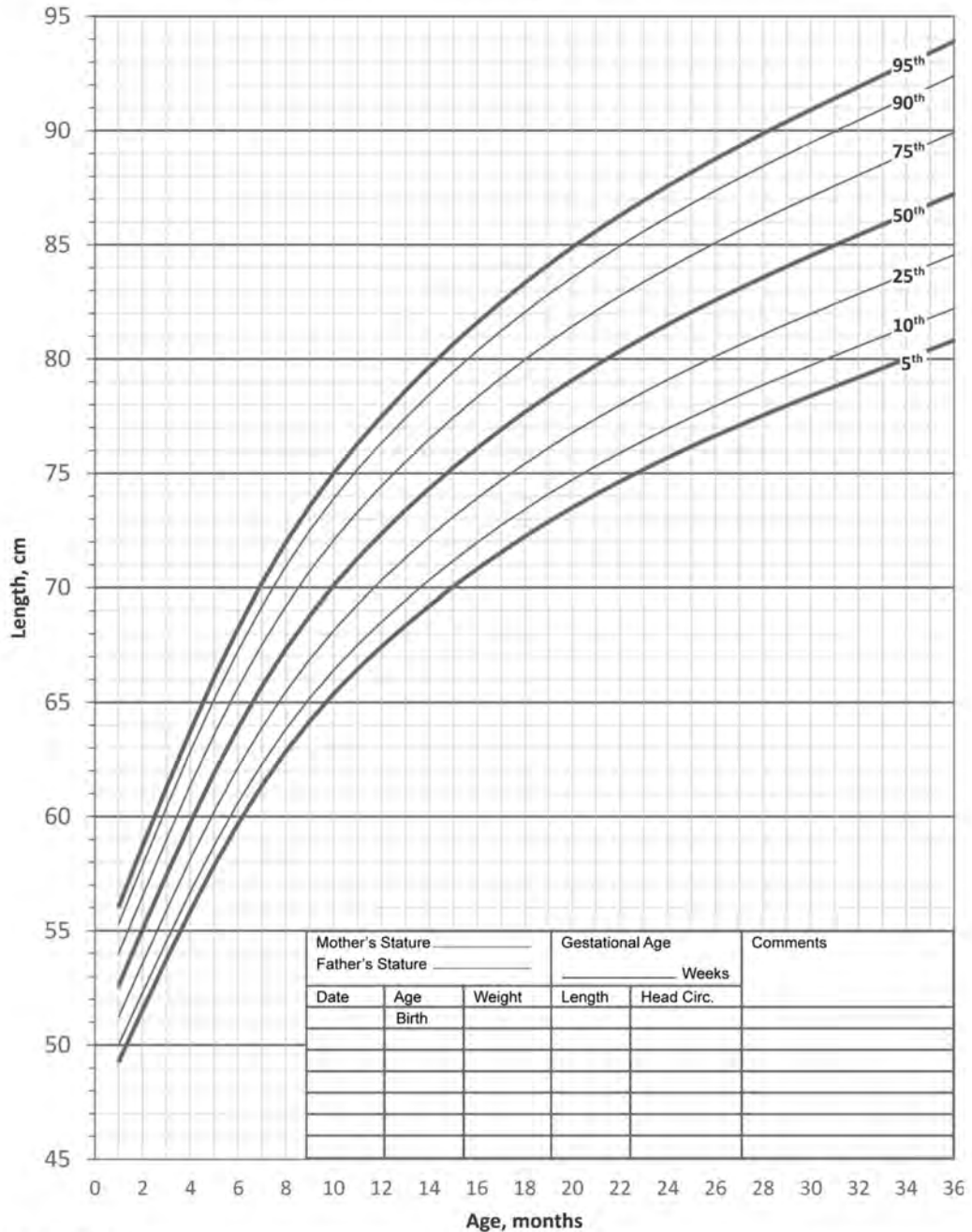
Do you have the right size? Remember, it should be COMFY:

- C - Centered nipple which moves freely
- ☉ - Only a little or no areola tissue is pulled into the tunnel
- M - Motion of the breast is gentle and rhythmic with each cycle of the pump.
- F - Feels comfortable while pumping.
- Y - Yields a well-drained breast.

Growth Charts for Children with Down Syndrome  
 Birth to 36 months: Boys  
 Length-for-age percentiles

Name \_\_\_\_\_

Record \_\_\_\_\_



Published October 2015.

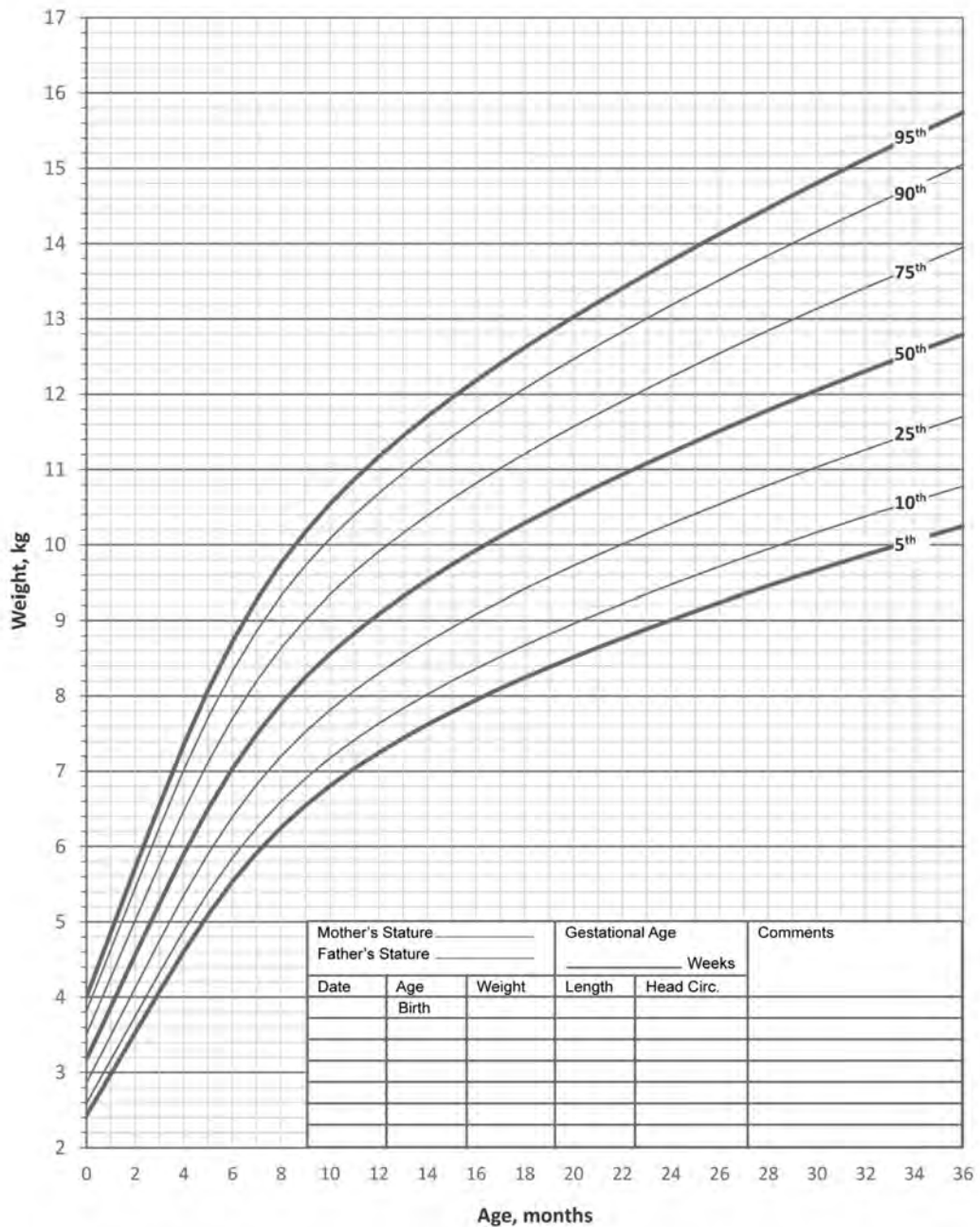
Source: Zemel BS, Pipan M, Stallings VA, Hall W, Schgadt K, Freedman DS, Thorpe P. Growth Charts for Children with Down Syndrome in the U.S. Pediatrics, 2015.

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Growth Charts for Children with Down Syndrome  
 Birth to 36 months: Boys  
 Weight-for-age percentiles

Name \_\_\_\_\_

Record \_\_\_\_\_



Published October 2015.

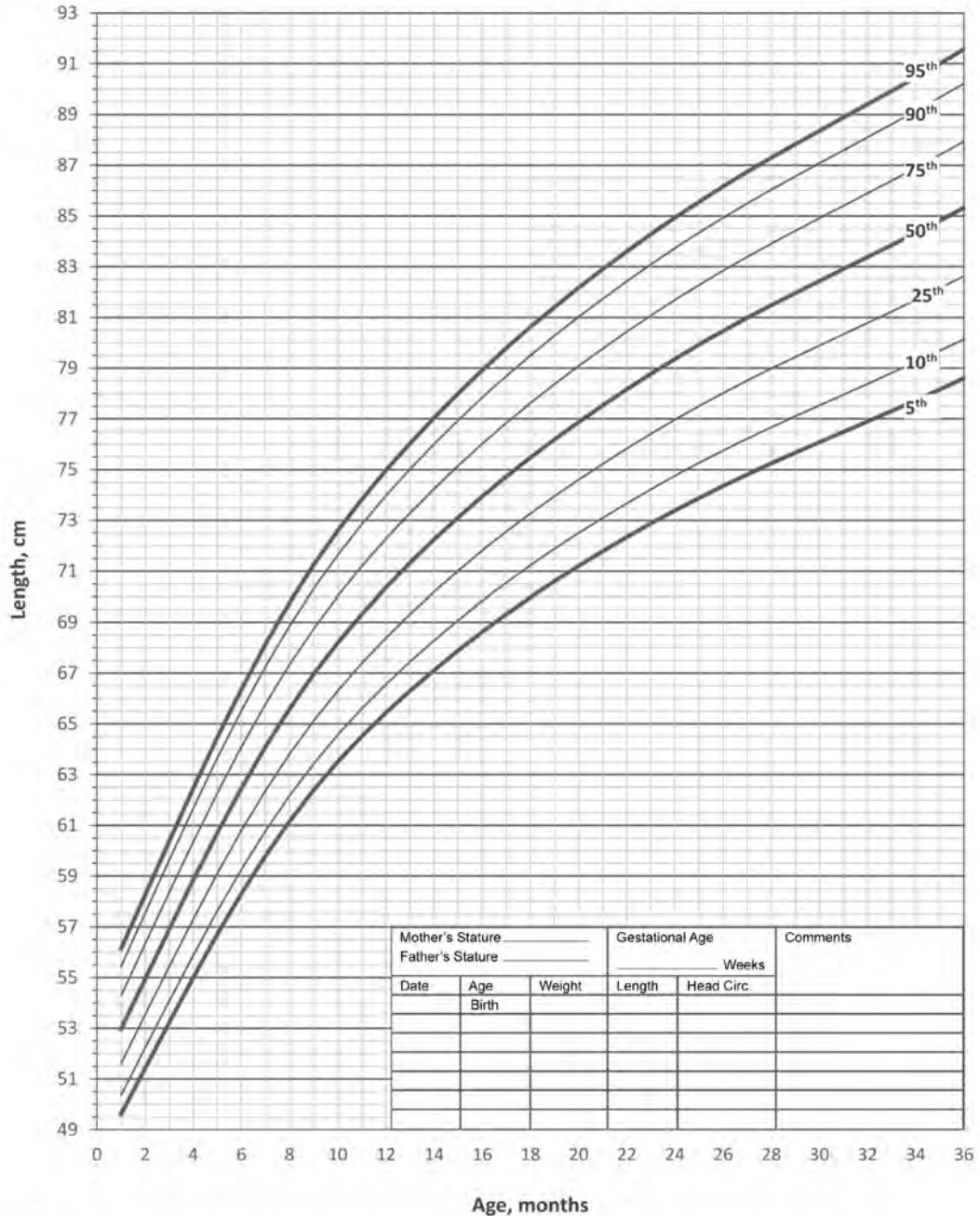
Source: Zemel BS, Pipan M, Stallings VA, Hall W, Schgadt K, Freedman DS, Thorpe P. Growth Charts for Children with Down Syndrome in the U.S. Pediatrics, 2015.

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Growth Charts for Children with Down Syndrome  
 Birth to 36 months: Girls  
 Length-for-age percentiles

Name \_\_\_\_\_

Record \_\_\_\_\_



Published October 2015.

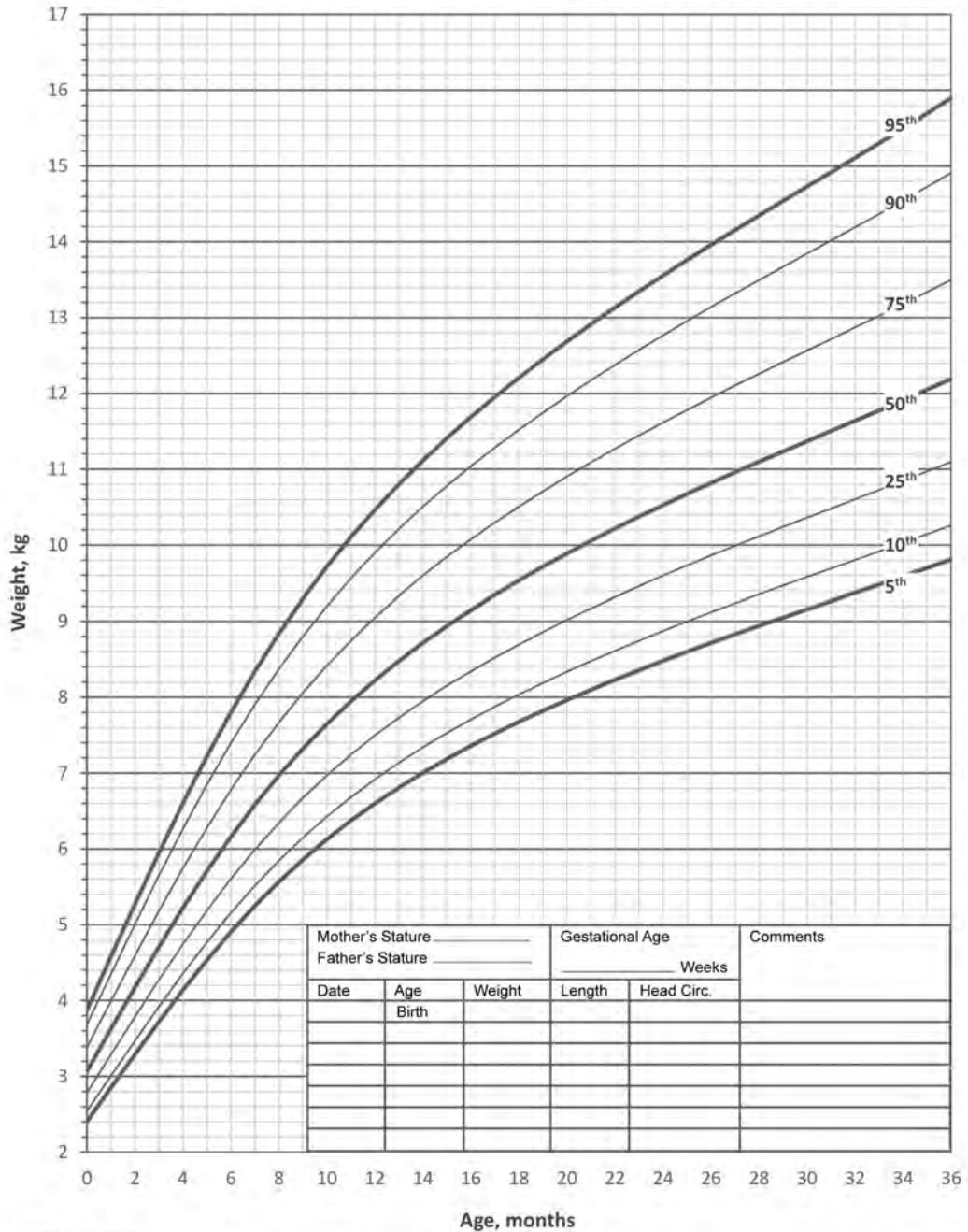
Source: Zemel BS, Pipan M, Stallings VA, Hall W, Schgadt K, Freedman DS, Thorpe P. Growth Charts for Children with Down Syndrome in the U.S. Pediatrics, 2015.

CS260242-B

Growth Charts for Children with Down Syndrome  
 Birth to 36 months: Girls  
 Weight-for-age percentiles

Name \_\_\_\_\_

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# ILCA's INSIDE TRACK

a resource for breastfeeding mothers

A Publication of the International  
Lactation Consultant Association



## Using Your Hands to Express Your Milk

By Anne Merewood, PhD, MPH, IBCLC, and Jane Abeel Morton, MD, FABM

Although in many countries women use breast pumps to express their milk, recent research shows that using your hands can work just as well—even better when you need to remove early milk (colostrum) in the first 3 days after birth. The following information should help you to learn this simple technique:

- It can be useful to hand express in the first 3 days because the amount of milk you remove during this time affects what you make later on: hand expressing now can boost your long term supply.
  - Especially in the early days, hand expression often works better than pump suction.
  - Once your supply goes up, you can often get more milk if you use a pump *and* your hands at the same time.
  - Once your milk comes in, or if you are apart from your baby for some time, your breasts might get hard (“engorged”). Hand expression helps you to soften the breast and get the flow of milk going. This also makes it easier for the baby to latch on.
  - In an emergency, you will be able to remove milk without a pump.
  - If your milk supply drops, you can hand express a little bit (like a teaspoon) from each breast a dozen times a day and this should help your supply go up again.
2. Form a “C” with your fingers about an inch back from the edge of the dark area around the nipple (the areola) with your nipple midway between your thumb and index (pointing) finger. Then,
    - **PRESS** back toward your chest.
    - **COMPRESS** your breast with the soft pads of your thumb and index finger. Continue to press backward (inward) and avoid sliding your fingers down toward the nipple.
    - **RELAX** the pressure and start over.
    - **PRESS ... COMPRESS ... RELAX**
  3. Go back and forth from 1 breast to the other (right, to left, to right) with up to about 10 compressions on each breast before switching. As you learn to express your milk, you will discover the “sweet spots” where the milk drops will come out the easiest.
  4. If you can, collect your milk into a spoon or, as you get more, into a small cup or into the breast shield of the pump.

### How Do You Hand Express Early Milk?

In the first days, expect to express only drops. Keep it simple; you can express when you have a moment without trying to collect milk or worry that you are “wasting” it. The more you remove, the more you will produce later. Practice in the shower, or after you’ve put your baby down, at least 6 times a day. Here’s how to begin:

1. Place your hands over your breasts and gently massage for just a minute.



Hand expression of colostrum (early milk) in first 3 days



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In the first 3 days after birth, you may see only drops. But after a few days, you will start seeing sprays of milk. As with everything, "practice makes perfect," so hang in there until it works for you!

For the step-by-step demonstration of **how to hand express**, you can watch a free demo at <http://newborns.stanford.edu/Breastfeeding/HandExpression.html>.

## How Can You Combine Hand Expression with Electric Pumping, Called "Hands-On Pumping"?

Instead of just relying on a pump's suction once your milk comes in, you will be able to remove more milk and drain the firmer areas around your breast by doing "hands-on pumping." This means compressing the breast and massaging at the same time you pump:

1. Gently massage the breasts.
2. Begin by pumping both breasts—at the same time if possible—with an electric pump. Also at the same time, use your hands to massage and compress milk out of the breasts, on 1 breast, then the other, back and forth. A hands-free pumping bra (or a sports bra with holes cut out) makes this easier to free up your hands. You will learn the best place to use your hands by feeling for areas of firmness and watching for sprays in the clear plastic connector.
3. Once the sprays nearly stop, take the shields off. Take a few minutes' break to massage your breasts, especially around the outer areas of your breasts.
4. Finish using the pump and your hands in a way that works best for you. Either pump 1 breast at a time using both your hands and the pump (single pump) or rely only on hand expression. Either way, go back and forth several times at least, from 1 breast to the other, giving each a short rest before returning.



Hands-on pumping of milk after day 3

Even though you will probably remove only a small amount of milk with step 4, you will be sending a strong signal to your breasts to produce more milk. Develop your own style of hands-on pumping and you will feel the difference when your breasts are well emptied. Using hands-on pumping, not relying only on pump suction alone, will increase milk production and increase the richness of your milk.

For the step-by-step demonstration of **how to do hands-on pumping**, you can watch a free demo at <http://newborns.stanford.edu/Breastfeeding/MaxProduction.html>.

Authors' Note: Photos and video clips courtesy of Jane Morton, MD, Breastmilk Solutions.

### Find Help Fast

An IBCLC is an "International Board Certified Lactation Consultant": someone with special training to help breastfeeding families. Go to "Find a Lactation Consultant" at [www.ilca.org](http://www.ilca.org) to locate a lactation consultant in your area. You can also ask your doctor or a nurse at your hospital.

### Your local lactation consultant:

Blank space for listing a local lactation consultant.





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**Down Syndrome Pregnancy**

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## About the Editor

Ella Gray Cullen, RN, is a Registered Nurse, Certified Lactation Consultant, and a trained doula. She is the mother of a daughter with Down syndrome and the founder and Executive Director of Julia's Way, a 501(c)(3), non-profit organization dedicated to reimagining life with Down syndrome.

## Praise for *Breastfeeding & Down Syndrome*

*"Breastfeeding babies with Down syndrome is not only possible, but important—a gift packed with health benefits for moms and babies alike. This book is an essential resource for all new parents who are beginning their remarkable journey with a newborn who has Down syndrome."*

— **DR. BRIAN SKOTKO**, MD, MPP, Emma Campbell Endowed Chair on Down Syndrome, Massachusetts General Hospital & Associate Professor, Harvard Medical School

*"This is a comprehensive guide for new moms (and their care providers!) on the breastfeeding journey with a new child with Down syndrome."*

— **JEN JACOB**, Executive Director: Down Syndrome Diagnosis Network, Author: *The Parent's Guide to Down Syndrome: Advice, Information, Inspiration, and Support for Raising Your Child from Diagnosis through Adulthood*

*"I am delighted to recommend wholeheartedly the comprehensive and supportive Breastfeeding & Down Syndrome to both families and the professionals who serve them. Why is it the best resource I've seen on nursing babies with Down syndrome? Its information is fully referenced and state-of-the-art. Its illustrations make its helpful strategies simple to use. Its Pro Tips from expert clinicians provide practical approaches to medically challenging issues. Its Mom Tips offer the perfect antidotes to common frustrations. And the wisdom and insights contained in its personal stories include a range of experiences that will benefit families and professionals alike. Thank you, Julia's Way, for creating this incomparable book!"*

— **NANCY MOHRBACHER**, IBCLC, FILCA, Author: *Breastfeeding Solutions* and the Breastfeeding Solutions smartphone app

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