



PREPARING TO BREASTFEED YOUR BABY WITH DOWN SYNDROME: A GUIDE TO TAKING YOUR BABY HOME

BY JILL RABIN, MS CCC-SLP/L IBCLC

September 18, 2017

This is the third in a three-part series on preparing to breastfeed your baby with Down syndrome, written specifically for women with a prenatal diagnosis by Jill Rabin, an International Board Certified Lactation Consultant and Pediatric Speech Pathologist.

Congratulations, it's time to take your baby home. What an exciting time for your new family! If breastfeeding did not work out quite as planned in the hospital, you may need continued lactation support at home. Many International Board Certified Lactation Consultants (IBCLC) can make home visits to assist your baby in transferring to the breast. Your hospital's lactation consultant or moms in your local Down syndrome (DS) community can often recommend someone experienced in working with babies with special feeding needs.

If milk intake and weight gain were the primary concerns while your baby was in the hospital, you might be feeling nervous about breastfeeding, worrying that your child is not getting enough to eat. Frequent weight checks are sometimes recommended in the first few days and weeks after discharge to confirm that your baby is receiving enough milk to gain weight and thrive. There are a variety of reasons that babies with Down syndrome may need to be supplemented with a bottle (with fortified breast milk or formula depending on his or her needs) after breastfeeding. Weighted feedings, when a baby is weighed before and after a nursing session, can help you and your lactation consultant determine if this is necessary for your baby. Weighted feeds are also a great way to see the progress that your baby is making from week to week and can prevent you from over-supplementing. You can also do weighted breastfeeding at home, by buying or renting your own scale. In addition to the scale, there are many breastfeeding smartphone apps, which track your baby's feedings, as well as the number of wet and dirty diapers. These records will reassure you and your baby's medical team that your baby is indeed taking in enough breast milk. We understand that

doing weighted feeds at home may seem overwhelming to you. If so, that's okay! Tracking the number of wet and dirty diapers should be enough for most babies.

Use of feeding equipment, such as a nipple shield or a supplemental nursing system (SNS) may be recommended by your lactation consultant to help get your baby to the breast. A nipple shield is a circular piece of silicone that goes over your nipple and may make latching to the nipple and sustaining a sucking pattern easier. A SNS is a thin plastic tubing system. One end is taped to your breast and the other is attached to a bottle of your pumped milk. The SNS allows your baby's sucking efforts, which may initially be weak or ineffective, to be rewarded with milk. The SNS also helps your baby establish appropriate suckling motions and encourages bonding. It has the added benefit of forming an association between being at the breast and having a full belly. Use of both the nipple shield and the SNS is often short term but can be vital in making the transition to breastfeeding exclusively. Even if your baby has a nasogastric tube or a G-tube in place, they can practice suckling at the breast. Skin-to-skin contact or "kangaroo" care, paired with suckling at the breast with or without the SNS may increase your milk supply and "set the stage" for breastfeeding until your baby becomes strong enough to start transferring milk effectively. "Babywearing" is an easy way to have skin-to-skin contact. Several types of carriers allow you to hold baby snugly against your bare skin while having your hands free. Babies usually love being carried close to their mother's bodies and it can be a simple and easy way to soothe and snuggle your baby. Baby Wearing International is an excellent resource and they have meetings in several locations worldwide. They even have scholarships to encourage mothers of children with special needs to wear their babies.

Babies with Down syndrome usually have low muscle tone and have to work harder to maintain their bodies in position to breastfeed. A good chair and a supportive pillow or a baby carrier to help position your baby will reduce the work your baby has to do to feed and will free up energy for oral motor muscles to engage in latching and suckling. Correct positioning helps the baby to latch onto the breast better and encourages optimal milk transfer. Many mothers find side-lying nursing to be a very helpful position for nursing their babies with DS. Also, if your child has torticollis or lip or tongue ties he or she might not be able to compensate as effectively for them as other children due to the low muscle tone. It is essential that any ties are reversed and torticollis resolved to allow your baby to breastfeed. This is where you, again, may have to advocate for your baby. Some medical professionals still believe that babies with DS cannot breastfeed and will not do a thorough assessment to verify that all reversible issues are discovered and corrected. If your baby is having a difficult time nursing and no one on your medical team mentions assessing your baby for these issues, please ask them to do so.

While working to transition your baby to the breast, you will have to pump to establish and maintain your milk supply. This issue will be addressed more fully in a future article but you can also find valuable information in our 2nd article in this series and in our brochure, *Nursing Down Syndrome: A Short Guide to Breastfeeding Your Baby*. It can be a challenge to establish your supply when your baby is not able to directly nurse or with a baby with a weak or ineffective suck. If needed, you can talk to your lactation consultant about dietary and natural ways to enhance milk production. It is important to remember that these methods do not work in isolation and still require frequent and

consistent pumping with an electric breast pump. It may be useful to ask your local DS organization or medical program if there are moms in your area who would be willing to support you through this process. There are also many social media sites that can also provide support and encouragement, although it's good to remember that every feeding case is different and these are often moms and not medical professionals giving advice.

You may require ongoing support from the lactation consultant and speech pathologist, but with time and patience most babies with Down syndrome can successfully transition to breastfeeding. In addition to working with these feeding specialists, 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 in a prone position or on their tummy. However, frequent tummy time exposure is critical and will help improve their trunk and shoulder strength, which in turn, results in improved jaw and tongue function for feeding. You can even practice skin-to-skin contact and tummy time at the same time by lying on your back and having the baby on your belly or chest. Hold onto your baby securely and talk or sing to him or 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.

It is important to contact your local early intervention (EI) program as soon as you return home. Your pediatrician can make a referral if one wasn't made while your baby was in the hospital. You should arrange a developmental assessment with an early intervention team as early as possible. This team should include, but is not limited to, a developmental therapist, speech pathologist, and physical therapist. Occupational therapists and dieticians may be needed as well. It is important to have these evaluations take place right away to assist your baby in developing to his or her full potential and to provide you with ideas for positioning, playing, and feeding. They will instruct you on how to do "tummy Time" with your baby as this will have a positive impact on your baby's development and feeding skills, as previously mentioned.

Possible medical complications, such as heart and respiratory issues, prematurity, low tone, and excessive sleepiness, can make the initiation of breastfeeding difficult. It is possible that you may need to pump for an extended period of time until your baby can successfully transition to the breast or if, for some reason, your baby is not discharged from the hospital at the same time as you. Sometimes babies with DS are not fully able to breastfeed exclusively until they are three to four months of age. Maintaining your milk supply is the key to ensuring that transition to breastfeeding is possible when your baby is ready. This is often best done by pumping frequently with a hospital-grade breast pump. You may need to continue pumping eight to twelve times a day if you are exclusively pumping. Pumping after each nursing session is important if your baby is still not strong enough to fully empty your breasts. Your baby may initially have difficulty transferring sufficient milk from the breast due to fatigue, low tone, or weak sucking reflex. For these reasons, in addition to medical complications, babies with DS often require bottle feedings of expressed breast milk to receive the necessary daily calories, at least until they get strong enough to nurse efficiently. One thing that may reassure you is that babies with Down syndrome don't appear to have as much difficulty transitioning to the breast after receiving bottle feedings as other children. There also

doesn't seem to be a "magic window" for children with Down syndrome to learn to breastfeed and most tend to "get it" within the first few months.

The key to breastfeeding your baby with Down syndrome is being prepared and understanding the obstacles that you may encounter. You may need to strongly advocate for your baby as there are still health care professionals who are unaware that most babies with DS can successfully breastfeed. Surrounding yourself with knowledgeable health care professionals and a strong support network will generate positive results for you and your baby. Breastfeeding is not only possible for your baby with Down syndrome but is an important and therapeutic starting point for them. With the countless benefits of breast milk for your baby, in addition to the oral structural changes that can result from the act of breastfeeding, you are getting your baby off to a great start. While it may take them a little longer to transition to exclusive breastfeeding, and possibly require a little more intervention from professionals, it is definitely an attainable goal!