



# PREPARING TO BREASTFEED YOUR BABY WITH DOWN SYNDROME: A PRENATAL GUIDE

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*This is the first 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.*

So you know in your pregnancy that the baby you're carrying may have Down syndrome (DS). You had every intention of breastfeeding this baby, especially if you have other children that you have breastfed previously. You may be asking yourself, *can this baby breastfeed as well? Will having a diagnosis of Down syndrome mean my baby won't be able to breastfeed?*

Like everything in life, being prepared is essential. This is true whether you are training for a marathon, traveling to another country, or having a baby. While there have been many positive changes in respect to medical professionals and their understanding of the capabilities of little ones with Down syndrome, there is still a lot of misinformation about whether they can successfully breastfeed. I am here to tell you that they absolutely can, and in some instances they will transition to the breast just like any other baby.

There may, however, be little bumps in the road that can complicate breastfeeding or delay its onset and smooth transition. If your baby is born prematurely or has a heart or other medical condition at birth, this can prolong his or her discharge from the hospital and interrupt the feeding process. Also, a combination of low muscle tone, poor endurance, weak suck, and excessive sleepiness, often associated with newborns with Down syndrome, can further impact the feeding process. Some babies with Down syndrome may initially require nasogastric tube feedings and even bottle feedings. However, over time, with the right guidance from a lactation consultant, most babies can transition to exclusive breastfeeding. Being informed on what you need to do and how to do it is

essential in making breastfeeding work. Your advocacy for your baby will start right at his or her birth, and sometimes even before. Educating others about what babies with Down syndrome can do may be part of the process. Not only is breast milk the best and healthiest food option for your baby with Down syndrome, but the process of breastfeeding itself can result in oral structural changes in your baby that can positively impact their breathing, palatal development, and future speech capabilities.

## HOW DO I PREPARE TO BREASTFEED MY BABY WITH DOWN SYNDROME?

To best prepare for breastfeeding your baby with Down syndrome, it is helpful you to take a breastfeeding class and understand how breastfeeding works. As the frequency of breastfeeding is different from formula feeding and you don't have a bottle to look at as an indicator of how much your baby consumed, it's essential to know how many feedings your baby needs in 24 hours and how to determine appropriate output. You also want to check prior to delivery if your insurance will cover the cost of a breast pump. If for any reason your baby needs to be separated from you after birth, or you need to express breast milk long-term, it is essential for you to have a hospital-grade electric breast pump. A hospital-grade electric pump is the strongest pump available and will ensure you can maintain your milk supply over an extended period of time. Establishing and maintaining your milk supply is key, until you can be assured that the baby is transferring milk adequately. You also might want to contact the hospital where you are delivering and speak to their lactation consultants prior to your delivery. Let them know you may require some extra assistance as your baby has Down syndrome. Just because your baby has this diagnosis does not necessarily mean that he or she will have feeding issues, but if breastfeeding is a priority, then it is best to be prepared.

In addition to ensuring there are lactation services available at the hospital where you are delivering, you want to secure lactation follow-up for when you get home, for ongoing support and assistance, if required. When looking for a lactation consultant, you want to seek out someone who is an International Board Certified Lactation Consultant or IBCLC. Ask them if they have experience with working with babies with Down syndrome, as they have to understand how low muscle tone and possible accompanying medical issues can impact the feeding process. Experience with management of feeding a baby with Down syndrome is key. This may involve extended time, follow-up, and use of various feeding equipment, such as a digital scale, nipple shield, and supplemental nursing system. While some babies with Down syndrome may have no difficulty with transitioning to the breast, others may require more assistance. It is not unusual for some babies with Down syndrome to take up to 3 or 4 months to transition to exclusive breastfeeding. It is important to remember that there does not seem to be a "window" that closes for babies with Down syndrome and many frequently get the hang of breastfeeding as they get older and stronger.

This is also a great time to establish a support network. There are many organizations that can assist new parents who are having a baby with Down syndrome, as well as social media sites where you can communicate with other families. Establishing that support network early on can assist you in finding local resources, where other families can advise you on doctors, therapists, and lactation consultants they have used with their own children. Facebook groups such as [Down Syndrome](#)

[Diagnosis Network](#) have pages for expectant moms and a page dedicated to breastfeeding/pumping for babies with DS. Julia's Way, [Breastfeeding Children with Down Syndrome and/or Special Needs](#), and [Down Syndrome Babysteps](#), all have Facebook pages which allow for networking and support for breastfeeding. Remember that while these social media sites can provide great information and resources for you and your baby, you always want to contact a qualified professional, such as an IBCLC, if you encounter breastfeeding difficulties. Many moms on these sites are simply reporting their own personal experiences and every situation is different, so if you are having serious issues with feeding you always seek a professional opinion from an IBCLC.

The key to breastfeeding your baby with Down syndrome is being prepared and knowing about the obstacles you may encounter. We often need to strongly advocate for babies with Down syndrome as there are still health care professionals who are unaware of their ability to successfully breastfeed. Surrounding yourself with knowledgeable health care professionals and a strong support network will yield positive results for you and your baby. Breastfeeding is not only possible for your baby with Down syndrome but an essential and therapeutic starting point for them. While it may take them a little longer to transition to exclusive breastfeeding, and possibly require a little more intervention from professionals, it is almost always an attainable goal! Good luck and remember, you are not alone!