



Nursing Down Syndrome:

A short guide to breastfeeding your baby



Nicole Starr Photography

Congratulations!

By following the advice in this brochure you are taking an important first step toward successfully breastfeeding your baby with Down syndrome (DS). As with everything in life, being prepared is essential and we want to help you have the best chance for a happy, healthy breastfeeding relationship.

Most babies with DS can breastfeed just like any other baby. There may be bumps in the road that can complicate breastfeeding or delay its onset, but in most instances the baby can make a smooth transition to the breast. This brochure is designed to help you understand and prepare for any challenges you and your baby may face. In addition to this brochure Julia's Way is publishing a book dedicated exclusively to breastfeeding babies with Down syndrome, due out mid-2018.

Benefits of Breastfeeding Your Baby with Down Syndrome

- Breast milk provides an ideal source of nutrition, is easily digested, and is well tolerated by babies.
- Your baby may be born prematurely, with a less mature immune system. The antibodies in your breast milk provide a measure of protection against illness.
- The physical act of nursing is a type of speech therapy for babies with DS, shaping the upper palate, and laying the groundwork for future speech.
- It can encourage the important bond between a mother and her baby.

While You Are Pregnant

Make your medical team aware of your desire to breastfeed right from the start so they will be able to support you and your choices. Additionally you can:

- Take a breastfeeding class to better understand how breastfeeding works.
- Call your health insurance provider to check what your policy covers for breast pumps. If you are separated from your baby after birth you may need a hospital grade breast pump to establish your milk supply or to express breast milk long term. Most insurance plans will cover a small, portable electric breast pump for personal use.
- Contact the hospital where you are delivering and speak to the lactation consultants and let them know your intentions and that you may require some extra assistance.

First Hours

After your baby is born there are several things you can do to get breastfeeding off to the best start.

- Breastfeed as soon after birth as possible, preferably within the first hour. This allows for early imprinting which makes each following breastfeeding attempt easier.
- If your baby can't be breastfed soon after birth, you need to start pumping, ideally within three hours of delivery. This will help you establish your milk supply and will stimulate on-going milk production. Most NICUs have hospital-grade pumps available and can provide you with a pumping kit to get started.

(continued on back)

- Pump at least 6-8 times a day to establish an adequate milk supply. This will ensure that you will have the opportunity to transition your baby to breast in the future.
- Request assistance from the hospital's lactation consultants right away, especially if you are having difficulties. They may use a variety of different devices that can help to facilitate breastfeeding such as a nipple shield or supplemental nursing system (SNS). Ensure that you know how to use these before you leave the hospital.
- If your medical team wants to keep a close eye on intake, request pre- and post-breastfeeding weights to assess how much your baby is drinking.
- In many hospitals, a speech pathologist or feeding team may collaborate with the lactation consultant to help your baby transition to oral feedings safely. Make sure everyone on the team is aware of your desire to breastfeed.



COMMON CHALLENGES

These challenges may seem overwhelming at first but many can be overcome with time and support.

- Prematurity
- Heart or other medical conditions
- Low muscle tone
- Poor endurance
- Weak suck
- Excessive sleepiness
- Lip or tongue tie (not more common but can be more difficult to overcome when combined with other challenges)

Using the Breast Pump

Julia's Way surveyed mothers of babies with DS and discovered that up to 70% of them have to pump at some point during their baby's breastfeeding journey. Pumping can be tiring and it may be challenging to establish your milk supply if your baby cannot nurse directly, but it can be done!

To get the most out of your pumping sessions, remember:

- A hospital grade pump can help establish your supply in the first few weeks.
- Looking at a picture of your baby while you pump can encourage let down.
- Relaxing music has been shown to have a positive effect on milk supply.
- Hand expression can be more effective at milk removal in the first 24-48 hours. Your lactation consultant can instruct you.
- When establishing supply, more frequent pumping is more beneficial than longer pumping sessions.
- Massaging your breast for a few minutes before you start pumping can encourage let down.
- Try the "milk shake"! Lean forward and let your breasts hang down and gently shake them back and forth. This is thought to stimulate the breasts and release the milk droplets from the walls of the ducts.
- Stay hydrated and maintain a healthy diet. Protein-dense foods are important for good milk supply.
- Consider purchasing two pumping kits to cut down on washing parts as frequently. Make sure to read the CDC's guidelines for keeping your pumping parts clean.

Going Home

You may find it easier to concentrate on your breastfeeding relationship once you are in a familiar environment.

- Track your baby's breast milk intake and wet/soiled diapers in a paper journal or through a smart phone app.
- Consider purchasing or renting a digital scale to do pre- and post-breastfeeding weights at home to ensure that your baby is transferring enough milk.
- Find a comfortable chair and a good pillow to support you and your baby. Good positioning helps the baby latch on to the breast better and allows for optimal milk transfer.
- Contact your local early intervention program when your baby is born and arrange to have a developmental assessment as soon after discharge as possible. This team will assist your baby in developing to their full potential and can provide you with ideas for positioning, play, and feeding.

For more information, support, and resources visit www.juliasway.org or email love@juliasway.org. We would love to hear about the successes and challenges you've had during your breastfeeding journey.