

***Breastfeeding a Baby with
Down Syndrome***



Canadian
Down Syndrome
Society

Société canadienne du
syndrome de Down

Acknowledgements

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Breastfeeding a Baby With Down Syndrome: A publication by
the Canadian Down Syndrome Society

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"Babies with Down syndrome need what all babies need – cuddles, nourishment, and love."

Congratulations!

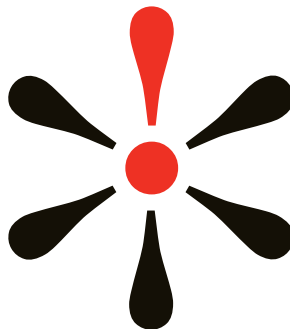
Congratulations on the arrival of your baby! You are about to embark on an incredible journey filled with love and learning. While you may be surprised to learn your baby has Down syndrome, know that your little one will be a wonderful addition to your family.

This booklet will explain how breastfeeding can be a valuable and rewarding part of caring for your baby and contribute to your child's well-being. It also provides information on techniques to help your baby learn to breastfeed effectively.

Benefits of Breastfeeding

Breastfeeding a baby with Down syndrome is not only possible, but provides important benefits to both mother and child.

1. Human milk will boost your baby's immune system and protect against numerous auto-immune disorders such as celiac disease, asthma, and allergies. This is especially important for babies with Down syndrome since they are prone to respiratory and viral infections.
2. The repetitive sucking action during breastfeeding will strengthen your baby's lips, tongue, and face. This serves as a stepping stone for future speech development.
3. Breastfeeding is convenient! It is always available and contains all of the nutrients, calories, and fluids your baby needs.
4. Hormones produced during breastfeeding help your uterus to shrink back to the size it was before pregnancy.
5. Breastfeeding has been shown to reduce the risk of developing ovarian cancer and breast cancer.
6. Breastfeeding provides warmth and closeness. The physical contact helps create a special bond between you and your baby.



Breastfeeding Your Baby

The early days of breastfeeding are a time for you and your baby to get to know each other and learn to breastfeed effectively. Every nursing couple must make some adjustments during this time because every baby is unique. As you get acquainted with your baby, you will discover that babies with Down syndrome have physical characteristics that may have an impact on breastfeeding. While you probably will not encounter all of the challenges discussed here, understanding your baby's particular needs will help you to get breastfeeding off to a good start.

Positioning

Positioning your baby in a comfortable and supportive arrangement will preserve her energy and allow her to use this energy for feeding. Proper positioning will also help your baby get more milk for her efforts and better stimulate your milk supply.

- * Use pillows as needed to support your baby's body so her mouth is level with or slightly below your nipple.
- * Always hold your baby very close into your body for comfort and the best latch.
- * If your muscles feel strained, use pillows to help support your back, shoulders and arms. When your baby is tucked right in against your body, your arms aren't working so hard. Remember to relax! Your milk will flow best when you are calm and comfortable.

Latching on

- * Expressing some milk onto your nipple prior to breastfeeding may encourage your baby to latch on.
- * Ensure your baby gets a large mouthful of breast tissue. This will help your baby draw the milk out and stimulate the breasts to produce more.
- * To do so, hold her in a comfortable position, using your free hand to support your breast in the C-hold – thumb on top, fingers underneath – well behind the areola, the pigmented area around your nipple. Tickle the baby's lips lightly with the nipple and wait for her to open her mouth very wide, then pull her in close to your breast with the nipple pointing up into her mouth. If it doesn't quite work the first time, be patient and try again.



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Signs of Effective Breastfeeding

Perhaps the most obvious sign of effective breastfeeding is adequate weight gain in your baby. This should not be solely relied on, however, as babies with Down syndrome often gain weight at a slower rate than traditional milestones suggest. You cannot actually see the milk going into your baby, but here are things you can check for to ensure your baby is nursing effectively:

- * The baby has taken a good-sized mouthful of breast, so that her gums can compress the milk ducts that lie behind the nipple. The nipple is drawn far back in her mouth as she sucks.
- * The baby's chin is pressed into the breast and her nose is lightly resting on the breast.
- * The baby's tongue is cupped under the breast. You can see the tongue by pulling down gently on the bottom lip. The tongue should be visible between the breast and the baby's gum.
- * The baby's mouth has a secure seal on the breast. To release the seal when taking your baby off of the breast, try slipping a clean finger in the corner of his mouth, or press down gently on the breast near his lips.

Typically, it takes one to two minutes of your baby on the breast before let down occurs. During this time, the baby will suck rapidly, pausing after every 3 or 4 sucks to swallow and breathe. After the let down, sucking becomes slower and longer with a pause between most sucks. Listen for sounds of swallowing coming from your baby, approximately two to three seconds apart. Swallowing noises may be subtle and difficult to hear. You may find it helpful to have a partner or professional listen with a close ear the first few times you breastfeed. You can also try placing a finger lightly under your baby's chin – you should feel a delicate, repetitive movement as she swallows.

Potential Influences

Low Muscle Tone

As babies with Down syndrome often have low muscle tone, including reduced muscle strength in their tongue and lips, good head support is particularly important for your baby during breastfeeding. There are a variety of ways you can hold your baby while breastfeeding to support his head, neck, and upper back. Applying gentle, steady support to the base of your baby's head will help him to suck well without tiring. However, it is important not to put too much pressure on the back of the baby's head, as it can cause a poor latch.

Cross-Cradle Hold

The cross-cradle hold allows you to provide your baby good head support during breastfeeding. Hold your baby using the arm opposite the breast at which he will feed (i.e., the right arm when nursing at the left breast).

Position your hand to support his neck and head, like a shirt collar, while his body extends along the length of your forearm. The free hand will hold and position the breast. This position offers a good view of your baby at the breast and helps you to control and support both his head and body. Support the base of your baby's head so he can still tilt it back slightly. Avoid placing any fingers above his ear level.



Football Hold

The football hold also allows you to support your baby's head and gives you a good view of his face so you can watch for latch-on and sucking problems.



To feed on the right breast with the football hold, clasp your baby's torso under your right armpit. His legs will not be visible as they will be tucked behind your arm, along your side. Use your right hand to position his head to your breast.

To feed from the left breast, hold his torso under your left armpit and use your left hand to position his head onto your left breast. You will find it helpful to support your baby with a pillow at your side to ensure you and your baby are most comfortable. Applying gentle, steady support to the base of your baby's head will help him to suck effectively without tiring; you should be supporting the upper back area and neck, keeping his head steady with your fingers below his ears.

Dancer Hand Position

Another way to physically support the baby's sucking is to use the "dancer hand" position. This position is particularly useful for babies with low muscle tone.

To do so, support your breast using the C-hold (thumb on top, four fingers underneath). Slide the hand supporting the breast forward, supporting the breast with three rather than four fingers. Your index finger and thumb should now be free in front of your nipple. Bend your index finger slightly so it gently holds your baby's cheek on one side while the thumb holds the other cheek. The index finger and thumb form a "U" with the baby's chin resting on the bottom of the "U". The "dancer hand" position keeps the weight of the breast off the baby's chin and helps him hold his head steady while nursing.

Positions to Improve Milk Flow

- * If you find your baby seems to be drinking too quickly, position your baby “up hill” so her throat and neck are higher than your nipple. You can lean your body farther back by sitting in a rocking chair or leaning on a supportive pillow, or have your baby sit up in a straddle position on your lap. This position will help avoid gulping and coughing, which may be a problem for some babies with Down syndrome.
- * If your milk flows slowly or moderately, try starting your milk flow prior to putting your baby to the breast. Gently massage the underside of your breast to encourage your milk to let down. Placing a warm, damp face cloth on your nipple may also promote milk let down.



Sleepiness

Many babies with Down syndrome are very sleepy the first few weeks after birth, which can hinder their feeding routine. To establish your milk supply and ensure your baby gets enough milk, it may be necessary to wake him to feed every two hours, or at least 8-12 times a day. It may also be challenging to keep your baby awake for the duration of the feeding. The hind milk, obtained in the latter part of the feeding, is higher in fat and calories which are important for growth. It is important that your baby receive these nutrients.

There are a variety of tips you may use to keep your baby awake during breastfeeding:

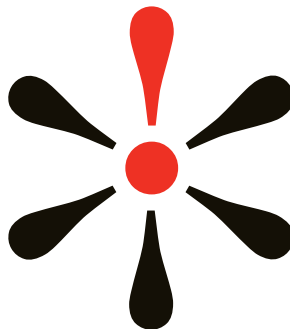
- * Dim the room so your baby doesn't have to close his eyes against the light
- * Remove his clothes before breastfeeding to keep him cool and aware
- * Stimulate his senses by lightly touching the edge of his outer ear, stroking his arms, and talking to him during feeding. These touches and sounds will distract him from becoming drowsy and help him to focus on the task at hand
- * Try placing a cool, damp washcloth on your baby's belly, leg, or forehead. The cool sensation is bound to wake him up



Your baby can be encouraged to continue active suckling, and get more milk, by using breast compression and/or switch nursing.

Breast compression is done when the baby is breastfeeding but sleepy or not actively sucking. Use one hand to squeeze the breast firmly but not so hard that it hurts. The baby should start to swallow. Keep squeezing until the baby stops or slows down his sucking again. When you release the pressure, the baby will increase swallowing; once it slows down, squeeze again. Repeat the squeezing and releasing until it no longer works, and then offer the baby the other breast.

To try switch nursing, watch for the baby to lose interest in active suckling, then slip a finger in the corner of his mouth to break the suction and offer the other breast; he should nurse more vigorously. When his sucking slows again, switch him back. Keep repeating this until he seems satisfied. You can combine breast compression and switch nursing or do just one or the other. You will see what works best for your baby.



Tongue Thrust

Babies with Down syndrome may have a protruding tongue that can push against your nipple. This may pose a challenge for your baby when latching on, as he may push the nipple out of his mouth. If your baby is latched on properly, you should be able to see his tongue cupped under the breast, resting on his lower gum.

When you are latching your baby onto the breast, watch for his mouth to open wide, with his tongue forward and down. To encourage your baby to bring his tongue forward, use your index finger to press down softly on the baby's chin while he latches on. This opening of the jaw will cause the tongue to protrude further out of his mouth.

Don't be disheartened if your baby needs some initial encouragement to keep his tongue down while latching on. Facilitating oral stimulation can help move the tongue into position to breastfeed. To do so, place your index finger on the center of your baby's tongue, encouraging the tongue to form the shape of a trough. Push down on his tongue while gradually pulling your finger out of his mouth. Try repeating this exercise several times before latching your baby onto the breast.

Weight Gain & Supplementing

Four ounces a week is considered adequate weight gain, but it is not unusual for a baby with Down syndrome to gain slowly even when she is receiving enough nourishment. If she is not being given anything but your milk, a baby who is getting enough to eat should have six really wet diapers (more if using cloth diapers) and three to five bowel movements a day (beginning after the fourth day). An older baby may have bowel movements less frequently, but they should be plentiful.

A baby who is not nursing effectively or long enough may not be getting the hind milk, the high-calorie milk that comes toward the end of a feeding. Sometimes using breast compressions, massage or switching sides twice during the feeding will help your baby to obtain that higher calorie milk. If that doesn't enhance the baby's intake and weight gain, you can offer this hind milk as a supplement after your baby has finished nursing, to ensure she is receiving all of the nutrients.

It is better to avoid giving supplements in a bottle until your baby has been breastfeeding well for three to four weeks. While she is learning how to breastfeed, exposure to artificial nipples and a different type of milk flow may cause nipple confusion, since sucking at the breast is different than sucking on a bottle.

If you choose to offer your milk as a supplement, there are a variety of methods for you to choose from. If your baby can latch and needs supplements of either expressed human milk or formula, you can use a nursing supplementer or other method that avoids artificial nipples. The nursing supplementer is a small soft tube that rests on the breast like an “outer” milk duct. This method is helpful because the baby suckles at the breast while receiving the extra flow of milk from the small tube.

Bottles are difficult to avoid if the baby is unable to maintain an effective suckle at the breast. The need for bottles may diminish as your baby matures and his muscle tone improves and some mothers have found ways to bottle-feed in a manner that supports breastfeeding.

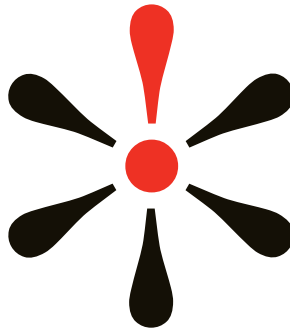
One size does not fit all; your family physician or lactation consultant will be able to offer you guidance on what techniques will work for you and your baby.

During the time that your baby is learning to breastfeed effectively, you may need to offer supplements after most feedings. Some babies nurse better if they get some of the supplement before they are put to the breast, rather than waiting until they are upset with hunger.



Support for Breastfeeding

All babies benefit from breastfeeding or receiving breast milk. Sometimes, information, support and encouragement are all that is needed to get over the challenge; sometimes, practical interventions are required; and other times, breastfeeding just doesn't work out. Support and information can be found at LLLC meetings or from LLLC Leaders. Lactation Consultants can assist with supplemental nursing devices and pumps. Your health nurse or doctor can provide information on other feeding options. Remember your baby thrives on your love as well as any nourishment that you give him.



A Mother's Story: Sonja

On a sunny day in June my husband, David, and I sat together on the edge of the hospital bed in shock and disbelief. The doctor told us that our tiny daughter, Ana Rose, born mere hours earlier, had Down syndrome. It was a complication free pregnancy with Ana and I had undergone a Caesarean section similar to the birth of my son – how could this be?

Our ecstasy quickly turned to heartache and worry; What is Down syndrome? Will Ana die? What did we do wrong? A thousand questions pierced my brain. The most prominent being, where will we go from here?

Prior to Ana's birth, I had breastfed our first son, Alexandar, with no difficulty or setbacks. I enjoyed breastfeeding my son; it was a unique opportunity for us to bond that he couldn't get anywhere else. In addition, the nutrients breast milk provided kept his immune system healthy and strong. I had planned on sharing this same experience with our daughter, Ana, and I wasn't going to let a determination of Down syndrome stop us.

The hospital staff assured us that babies with Down syndrome just don't breastfeed, but much to their dismay, David and I were persistent. Ana was connected to a feeding tube in the Intensive Care Unit, but we continued to travel to and from the hospital every few hours, night and day, in an attempt to feed Ana naturally. Regrettably she showed no interest in the breast. Day after day we introduced her to the breast and time and time again, she refused to latch on. I sadly watched as the milk dribbled down her cheeks. I felt hopeless.

After three days, David and I began to comprehend the fact that Ana may not breastfeed. We decided to feed Ana breast milk through a bottle, which we considered the next best thing. Unfortunately, Ana refused the bottle as well. I was devastated.

In the wee hours of day four of Ana's life, a nurse who had been supportive of our breastfeeding efforts all along, called to inform us that Ana was once again awake to feed. David and I got dressed and trekked over to the hospital under the night sky. I sat down in the ICU and thought I might as well try breastfeeding Ana one last time. As per usual, she declined the first breast I offered her. The nurse came over and showed me an alternative way to hold Ana. Much to my surprise, Ana opened her mouth wide and latched onto my breast. *Could this really be happening? Yes it is!* Just when we were ready to give up, Ana latched on. I was amazed! Tears ran down my cheek as my husband and I watched our baby girl breastfeed for the next twenty minutes.

Since that night in the ICU, our breastfeeding journey has had its highs and lows. Some days Ana latches on with ease, other days she refuses the breast altogether. It has taken a lot of time and patience, but now, at eight months old, Ana is latching on rather consistently.

Breast milk has greatly impacted Ana's development. Because of the nutrients it provides, Ana has already reached many of the developmental milestones for her age and she is a relatively healthy baby. The physical contact of breastfeeding has created a special bond between my daughter and me. Ana's tongue is stronger and protrudes less; I attribute this to breastfeeding, as well. It has been a long and sometimes difficult journey, but I am glad my husband and I stuck to it. I encourage other mothers to persist on the journey of breastfeeding, yet recognize that not all babies will breastfeed. Regardless of whether your baby is breastfed, bottle fed, or the alternative, remember that the most important thing you can feed your baby is love.



A Mother's Story: Julia

My daughter, Bethany Kathleen, who was born with Down syndrome, is our third child and our only girl. I had thoroughly enjoyed my breastfeeding experience with both of her vigorous older brothers, Joshua and Joseph. I had received a lot of help and good advice from the local chapter of La Leche League, worldwide proponents of breastfeeding. One of the bits of information I remember hearing from these experienced moms was that a baby who became accustomed to the flow of a bottle could have a lot of difficulty learning to breastfeed.

They did not know Bethany!

Bethany, born with Tetralogy of Fallot, a malformation of the heart, found it very difficult to nurse. Her muscle tone was very low. Even before my let-down reflex had kicked in, she would have worn herself out and fallen asleep. She was soon losing weight at an alarming rate. The nurses at the small rural hospital where Bethany was born were very frustrated, and became quite short-tempered with me when I told them, time after time, that Bethany had not fed. One nurse even grabbed my breast and tried to force it into my daughter's tiny mouth! I protested, insisting that I was experienced at breastfeeding, and that it was my child who needed further medical help.

Thankfully our doctor acted promptly, sending Bethany and me to the Children's Hospital in a larger centre nearby. In the neo-natal intensive care unit, Bethany was immediately given several feedings by "gavage" or nasal tube. Her weight loss was arrested within 24 hours. In ten days, Bethany was ready to come home.

All this time I had been providing milk for Bethany with the help of a mechanical breast-pump that definitely had me identifying closely with the dairy cows of our home community! When we left the hospital, I was given a hand-operated "hydraulic-action" pump, which worked very efficiently. I developed very muscular arms!

For two months I pumped and Bethany fed from a bottle. Rather than focusing my energy on the reality that my daughter could not breastfeed, I concentrated my efforts on ensuring Bethany was receiving the nutrients of breast milk, one way or another. A lot of milk ran out of her mouth when she bottle fed, and she never really seemed to be enjoying her meals. She ate a lot though, and I began to fear she might outstrip my ability to pump enough milk for her.

When Bethany was two months old, we took her and all her bottles and breast-pumping paraphernalia to visit friends out of town. One afternoon we arrived ahead of our friends at their home. The doors were all locked, and Bethany's equipment was inside! She became a little fussy, so I decided to offer her my breast just for the comfort of it. Much to my surprise, she latched on at once and nursed strongly, without the slightest dribbling!

Bethany never took a bottle again. She loved every minute of nursing and snuggling and rocking with me – so did I! I weaned her directly onto a cup shortly after her first birthday. I credit her relatively “healthy” first year to her being able to have my milk. Though her heart defect could not be repaired until she was three years old, and she remained very small, Bethany developed with few respiratory problems and no incidents of heart failure. She is now 28 years old and still loves to eat!

Our children are survivors, and more than that, often inspiring champions against great odds.



Resources for Parents

La Leche League Canada

P.O. Box 700

Winchester, ON, K0C 2K0

www.LLCC.ca

Tel: 613-774-4900

Breastfeeding Referral Service 1-800-665-4324

Canadian Down Syndrome Society

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Calgary, AB, T3A 5R8

www.cdss.ca

Tel: 1-800-883-560

References

La Leche League Canada. (1997) (2009). Breastfeeding a Baby with Down Syndrome [Brochure].

Australia Breastfeeding Association. (2007). Breastfeeding your baby with down syndrome [Brochure].

The Canadian Down Syndrome Society is a national non-profit organization providing information, advocacy and education about Down syndrome. The CDSS supports self-advocates, parents and families through all stages of life.

Our Vision: A proud Canada, where ALL are welcome, we embrace diversity and we value everyone equally.

Our Mission: To ensure equitable opportunities for all Canadians with Down syndrome. This means, to make sure all Canadians with Down syndrome have the right supports to give them the same opportunities as everyone else.

We provide:

- * Up-to-date information through the CDSS website for individuals with Down syndrome, their families, educators, caregivers and professionals
- * Publications, including the CDSS magazine and monthly newsletter, a toll-free information line: 1-800-883-5608, a resource centre and library, and a network of over 50 Down syndrome groups
- * New Parent Packages containing a wealth of information for new and prospective parents

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La Leche League Canada: Where breastfeeding and mothering connect

Talking to other mothers with up-to-date information about breastfeeding and basic infant needs helps to give mothers confidence. Correct information - even before her baby is born - can help a mother avoid common problems. La Leche League meetings provide a friendly place and an opportunity to share experiences.

La Leche League Leaders operate more than 160 La Leche League Canada (LLLC) Groups in communities across the country. Each Group holds monthly meetings where accredited Leaders facilitate informal, guided discussions. During these discussions mothers receive accurate, up-to-date and personalized breastfeeding information and support for their role as a breastfeeding parent. In addition, mothers are able to draw on the experience of other mothers who attend.

A wide variety of books, leaflets, DVDs and other resources of interest to parents are available through LLLC.

LLLC Leaders also offer email and telephone help to nursing and pregnant women who seek breastfeeding information. To find the La Leche League Canada Group in your area, contact us on line or in your local community:

We are at www.LLLC.ca or check public health resource lists or your local telephone book. You can also call the La Leche League Canada Breastfeeding Referral Service: 1-800-665-4324.

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