



Complex Child E-Magazine

www.ComplexChild.com

Breastfeeding Your Tubefeder

by Susan Agrawal

Before my daughter was born, I knew I wanted to breastfeed her. It was something that was very important to me, and something that I felt would give my daughter the best start in life.

But things did not turn out as expected, and my daughter was critically ill after birth, hooked up to a ventilator and many tubes and lines. Breastfeeding in the usual way was totally out of the question. Even after she recovered enough to begin receiving feeds, her suck was incredibly weak and her swallow uncoordinated. The likelihood of her breastfeeding or even bottle feeding was next to none.

I was incredibly emotional after her birth and the last thing on my mind was breastfeeding since we were entirely focused on fighting to keep her alive. But I was blessed to receive a visit in the hospital from a Lactation Consultant who specialized in babies with medical problems. She set me up with a breast pump and encouraged me to begin pumping for my daughter.

In many ways, pumping was actually quite cathartic. As my daughter lay in the NICU fighting for her life, I felt powerless to help her. Pumping breastmilk was something I could do for her. Not only that, it was something that might just help to save her life. Much research has been done on the subject, and babies who receive breastmilk while in the NICU have much lower levels of serious complications, such as those from NEC (necrotizing enterocolitis), an often devastating gastrointestinal disease, as well as lower rates of sepsis, infection, and shorter hospital stays.¹ Breastmilk is also the easiest thing to digest, which was very important for my daughter's recovering body.

It was not easy at the start. I was still physically recovering from a crash cesarean section under general anesthesia. I was not able to hold or pick up my daughter for the first 13 days of her life, and many days I was not even allowed to touch her for more than a few seconds at a time, leaving me emotionally distressed. Moreover, from both mechanical and emotional points of view, pumping definitely does not stimulate breastmilk production in the same way as a suckling baby held in your arms. The Lactation Consultant recommended a variety of strategies to me for increasing milk production (see below) and things started to improve.

By the time my daughter was ready to come home from the NICU, pumping had become second nature and feedings were going well. I pumped every two to three hours for the

first month, feeding my daughter through her feeding tube directly after pumping. My supply became abundant, with plenty of milk left over.

I continued pumping for my daughter for more than a year. The only reason I stopped was because I lost my supply shortly after I became pregnant with my second child. During the time my daughter received breastmilk through her feeding tube, she only had one cold. One cold in more than a year! She had no hospitalizations for illness during that year. For a child with as severe a brain injury as my daughter, this is pretty miraculous, since most children like her spend much of their first years in and out of the hospital. She was healthier than I was!

During my more than a year of pumping I learned a great deal about how to make pumping and feeding breastmilk through a feeding tube work. Here are some of the things I learned:

Get a Really Good Breast Pump

In general, exclusive pumpers need a hospital-grade breast pump that will pump both breasts simultaneously in an efficient manner. Pumping both breasts simultaneously will dramatically reduce the amount of time you spend pumping.

Current models include the Medela Symphony or Lactina [<http://www.medelabreastfeedingus.com/products/breast-pumps>] and the Ameda Elite [<http://www.ameda.com/products/hospital.aspx>], though some hospitals may use older models. Most hospitals and selected good pharmacies will rent these pumps for about \$50 a month. You will still need to purchase a kit to use the pump, which usually comes with breast flanges, tubing, valves, and other similar items. If you plan to breastfeed for a year or more, it may be to your advantage to purchase one of these pumps, though they typically cost as much as \$1000. If you are very fortunate, your insurance may cover the cost of renting or buying a pump.

The biggest disadvantage to hospital-grade pumps is their weight. These pumps are typically quite heavy and cannot be carried easily from place to place. While the size of the pumps has improved since I pumped for my daughter five years ago, the weight can still be a challenge, especially if you are also carting around a lot of your child's medical equipment. I used an inexpensive single breast pump for times when I needed to pump on the road and could not bring along my hospital-grade pump.

Find a Lactation Consultant

Breastfeeding, even in the usual way, can be very difficult for many mothers. A Lactation Consultant will help you to determine a good pumping schedule, check your pumping technique, set up your pumping system for home, and give you advice about increasing your supply. If at all possible, try to locate a Lactation Consultant who has experience with babies with special needs. We were blessed to have two great Lactation Consultants, one who was hospital-based and worked primarily in the NICU, and a

second one who was also a speech therapist and worked with families to try to transition to the breast.

You can find a Lactation Consultant by contacting La Leche League [<http://www.llli.org/>], calling your local women's hospital, or using this locator from the International Lactation Consultant Association [<http://www.ilca.org/falc.html>].

Get Support

It can be stressful enough just having a baby with medical problems. Add pumping around the clock to your schedule and the stress increases dramatically. It can be very helpful to join a support group that focuses on breastfeeding or pumping. When my daughter was first born, there was very little support available. Now there are many on-line sites that focus on exclusive pumping. There is a Yahoo group available for Exclusive Pumpers whose babies are unable to feed [<http://groups.yahoo.com/group/EPers/>] and an IVillage board on the subject [<http://messageboards.ivillage.com/iv-ppexclusumpump>]. Mothering magazine also has a discussion board which includes a very active "tribe" of exclusive pumpers [<https://www.mothering.com/discussions/showthread.php?t=462944>]. La Leche League offers several forums for special situations, including breastfeeding preemies and pumping.

Increase Your Supply

It is very common to have supply issues when you are pumping, especially when you are stressed out, sleep deprived, and scared. The best way to increase your supply is to stay well-hydrated and pump frequently. For me, this meant every two hours around the clock for the first few weeks. Eventually, by about two months, I was able to pump every four hours. Even when my daughter was a year old, I found I needed to pump once during the night and every four hours during the day to maintain my supply. Every time I pumped, I also drank a large glass of cold water to make sure I stayed hydrated.

When you have severe supply issues at the start, sometimes medication can be helpful. I was prescribed Reglan, which increases milk production as a side effect of its usual action. It made a huge difference for me. Another similar drug, Domperidone, works even better, but is not available in the United States. It can be imported from other countries.

Other things, including Fenugreek, Brewer's Yeast, Mother's Milk Tea (which typically includes fenugreek and blessed thistle), and Oatmeal, may be helpful in increasing supply. There are many articles available on this subject, including this one from Kellymom, a wonderful breastfeeding site [http://www.kellymom.com/herbal/milksupply/herbal_galactagogue.html], and this one from MOBI, an organization dedicated to overcoming breastfeeding challenges [<http://www.mobimotherhood.org/MM/article-diet.aspx>].

Dealing with Feeding Tube Issues

For the most part, putting breastmilk down a feeding tube is no different than using formula. If you do gravity or pump bolus (intermittent) feeds, all you need to do is place the breastmilk in the syringe or feeding bag as usual. If your child is on continuous feeds, it can be a bit more of a challenge since breastmilk naturally separates into layers, with the fat rising to the top, when it sits for a long period of time. I found that I did need to shake up the bag of breastmilk overnight several times. Usually if I shook it up right before I went to bed, in the middle of the night while pumping, and in the morning when I first woke up, it would stay reasonably well-mixed.

Thickening Breastmilk

Many children with feeding problems need to be on thickened feeds to help avoid aspiration and prevent reflux. Unfortunately, the enzymes in breastmilk often break down common thickeners and render them ineffective. The two that work best are Simply Thick and Hydra-Aid. If you will be feeding a bolus feed immediately, it is also possible to thicken with rice or oatmeal cereal before the enzymes kick in, but this definitely will not work for continuous feeds.

Increasing the Calories or Fortifying Breastmilk

Some babies, and especially preemies, simply need more calories than breastmilk can supply. If this is the case, you may need to find a way to fortify your breastmilk. Mothers with abundant supplies may be able to separate the watery foremilk that first comes out of the breast from the more fattening hindmilk and only feed the richer hindmilk. Other mothers may need to mix fortifiers into the breast milk, such as human milk fortifier or formula powder, to enrich the breast milk.

A recent development is the first breastmilk-based fortifier, made by Prolacta Biosciences [<http://www.prolacta.com/productinfo.php>]. This product concentrates donated breastmilk that has been prescreened, tested, and pasteurized into a fortifier. This product may be especially helpful for babies with complicated gastrointestinal issues.

When You Cannot Make Enough

Sometimes, despite your best efforts, you simply cannot make enough milk for your baby. Every little bit you do make will benefit your baby, so be proud of your accomplishment no matter what.

If you do want your baby to receive breastmilk but cannot make enough, your baby might be a candidate to receive donated breastmilk from a breastmilk bank. This site [<http://www.hmbana.org/>] lists some of the major banks in the United States, and this site [<http://www.milkbanking.net/index.php>] allows you to search by zip code. A prescription is required for breastmilk. Prolacta Biosciences also offers ready-to-feed

human milk based formulas, though at this time these are not readily available outside of hospitals.

It is also fine to supplement your baby with regular formula or, as the baby gets older, blended foods through the tube.

Every Bit Counts

When my daughter was first born, I set a goal to pump for her for three months, through the most critical time when her immune system was developing. Three months came and went, and I expanded my goal for another three months, trying to make it to the six-month mark recommended by the American Academy of Pediatrics. From that point on, I decided to just keep on going as long as I was able.

I won't say it was easy, so don't feel like a failure if you can only pump for a month or two. Every little bit counts. Every drop is as precious as gold. And every single drop you are able to give to your baby--even if it is only an ounce a day--is a miraculous contribution to your baby's health and development.

¹ Richard J. Schanler, *et al.* "Randomized Trial of Donor Human Milk Versus Preterm Formula as Substitutes for Mothers' Own Milk in the Feeding of Extremely Premature Infants." *Pediatrics* 2005;116(2): 400-6.