I’ve Just
Seen a Face

Chapter 15

But I Had Planned to Breast-Feed!

Nursing, Bonding, and the Flip Side

When we as parents learn the news of our baby's cleft lip and/or palate, we also find out that direct breast-feeding is probably not going to be possible. A cleft palate prevents a baby from forming a complete seal of the oral cavity, all but eliminating her chances of suckling at the breast. Medical people sometimes make the analogy of trying to draw liquid through a straw that has a hole in it: it doesn't work.

The loss of breast-feeding can mean a lot of different things to different people. Some mothers feel okay when they learn that they cannot nurse. Maybe they weren't planning on it anyway. The news may not be that big a deal. Thank goodness! Some adoptive parents and other parents, too, may have come to terms with feelings about nursing, even before they learned about their baby's CLP.

For others, particularly mothers, there is sadness, even grief. This news may mark the loss of a lifelong vision or at least a long-term assumption about our choices for our body and our baby. With cleft palate in the picture, mothers lose that choice. "Part of the relationship I'd dreamed of for nine months was over," writes Jessica Burfield, who, after six days of trying unsuccessfully to nurse her newborn, finally learned of her daughter's cleft-palate diagnosis. She realized she would never be able to nurse her baby.

"I couldn't believe how much it broke my heart" she said. "I cried and cried and cried over what I would never have."

What is this loss about? And what are some ways to move forward?

For the majority of parents I have spoken with, the act of breast-feeding offers two main opportunities: for a baby's nutrition and for mother-baby bonding. Decisions about a baby's nutrition—the choice between formula and breast milk—are personal, and in the case of cleft palate, unique. Many parents of babies with cleft palate choose to use formula. The few mothers who can pump milk and choose to do so—those heroic few—face all kinds of challenges (See more on this topic in the next chapter).

The loss of breast-feeding also means the loss of a fundamental way for mothers to bond with their babies—during the first year of life, no less, when a cleft-affected baby faces all kinds of special hurdles. If anything, parents and babies need *extra* opportunities for bonding during that time. "It is so heartbreaking," commented one cleft-team nurse. "Parents come to me and first, their world is kind of falling apart because they just learned about the clefts. Then you tell them about breast-feeding. It is just awful."

Sometimes, there is loneliness. One mother, Heather, recalled that her friends were having babies at around the same time. "All of them were nursing," she said. "It was hard to deal with accepting not being able to breast-feed. It was also hard not having anybody I could really talk with about not nursing, because all my friends were nursing." Just at a time when Heather needed someone to lean on to cope with these feelings, the people in her support network were engaging in the very activity that stoked her sense of loss.

Partners can feel it too. When I mentioned the question of nursing to one dad, he responded with immediate recognition, as if the topic were still fresh on his mind. "Our son is eight years old," he said, "and my wife and I still talk about this one." As a self-described hands-on parent, this father tried to do all he could to help his wife and baby during the early days after their son's birth. His wife, Cheryl, tried to nurse, he explained. But she seemed intensely frustrated by the failed attempts. "I felt helpless," he admitted. And her feelings—like those of so many other mothers—radiated to her intimate relationships.

Fortunately, researchers have studied the feeding and bonding activities of parents and their cleft-affected babies. A recent study shows that feeding a cleft-affected baby can cause great concern and frustration for parents, particularly during the first few days after birth. These difficulties can cause mothers to feel incompetent and can disrupt bonding with their babies during those first few days. Other studies show that mothers with cleft-affected infants feel less secure about their relationship with their babies and are more likely to show symptoms of post-traumatic stress and depression (see Chapter 11 for a broader discussion of bonding.)

When I first read these conclusions, I almost laughed out loud. If those researchers had been at our house during the first week after my daughter's birth, studying our feelings and behaviors with clipboards in hand, they would have had an easy time detecting those very emotions. We were totally stressed out! Did we have difficulties with feeding? Unfortunately, yes. Did I feel incompetent as a result? Absolutely, I did. Check! Check! All of the above.

Fortunately, there is a flip side to this coin. Research shows that the presence of a cleft and/or feeding difficulties do not affect the mother-infant bond at all over the long term—meaning months rather than weeks or days—as compared to the bonds of mothers with unaffected babies. In fact, scholars state that mothers of babies with clefts may even bond *more* with their infants than mothers of unaffected babies. And this bonding occurs without the mothers having nursed their babies! Caregivers may perceive their cleft-affected infants as especially needy, one study suggests, "leading to heightened activation of the 'attachment system' and caregiving behaviors that foster early secure attachment." We realize our baby needs extra help, in other words, and we develop a soft spot for her. This, too, is good news.

So, in the end, the loss of breast-feeding does not mean that we mothers lose a chance to bond with our babies; it's that we lose a chance to bond with our babies *this way*. And by extension, we lose an experience within our own bodies that facilitates that bonding. As much as I hate to say it, this loss is unique and cannot be taken back. But as any adoptive parent will tell you—or any partner or spouse, for that matter, who cares for a baby but does not nurse—there are many routes up the mountain. Skin-to-skin contact is an oft-discussed way to facilitate bonding, as is the simple but meaningful act of gazing into a baby's eyes. We can wear our babies on our chests. We can play with their feet or let them squeeze our fingers. And just wait until they smile! The opportunities are there, everywhere.

Also, there are ways to cope with this loss in the short term. The first is to honor the sad feelings. The American Cleft Palate-Craniofacial Association (ACPA) recommends: "Give yourself time and space to grieve this loss." Cleft specialists suggest seeking help from the professionals on a cleft team, particularly with feeding, but also with coping. One nurse recommended accepting help (even if we resist that idea) from friends and family with meals, cleaning, and other things, during the early days and weeks. While those forms of assistance do not necessarily relate to nursing or feeding the baby, they give us valuable time and space to clear our minds and work through our feelings. Last, we can cope by leaning on sympathetic friends and supportive people, particularly the ones who are good listeners (even if they happen to be nursing, themselves).

The feelings of sadness and grief may not go away for a while. And the stress of learning to feed the baby is real. At the same time, it might be comforting to know that despite all of the difficult feelings and stressful moments, bonding need not be diminished over the long term. Not by one tiny bit.