

Parenting Your Preemie with Sensory Issues

By Lindsey Biel, OTR/L

Parent #1: “*Effie* (chronological age: 10 months, adjusted age: 8 months) *was so tiny and so sensitive to everything when we finally left the hospital. She would drink from her bottle only if we huddled in a dark closet! She still doesn’t like it when I bounce or rock her. When I change her diapers, she fusses and sometimes screams. To get her to sleep at night, we need to make her room pitch black and keep the house absolutely silent. If I so much as walk to the kitchen for a snack after she goes to bed she’s up and complaining. I think if it were up to her, she’d just spend all day in her crib alone, sucking her thumb and looking at her stuffed animals.*”

Parent #2: “*Ben* (chronological age: 20 months, adjusted age: 18 months) *wakes up really crabby. Once he’s fully awake, though, he’s a whirlwind of activity, and he doesn’t stop for a second. He runs on his tiptoes from toy to toy, crashes into the couch, body-slams his brother, bangs into the wall, tackles me, and keeps on going and going. He is my magnificent, Energizer bunny, and we are all exhausted.*”



Both Effie and Ben show classic signs of sensory processing dysfunction, although their parents report very different ways of interacting with the environment. Effie avoids certain sights, sounds, touches, and movements, while Ben seeks out lots of vestibular and proprioceptive input.

All of us comprehend the world through our senses. We see things, we hear things, we touch things, we experience gravity, and we use our bodies to move around in the

world. All the sensory input from the environment and from inside our bodies work together seamlessly so we know what's going on and what to do. Sensory integration is something most of us do automatically. Usually, sensory input registers well and gets processed in the central nervous system, which integrates it smoothly with all the other senses. This process lets us think and behave appropriately in response to what's happening inside and around us.

Children born prematurely such as Effie and Ben, are at increased risk for sensory-based difficulties. A preemie with sensory issues can experience being rocked as an assault. Experiencing changes in head position may feel like bungee jumping. A lullaby may sound like thunder, and a flickering fluorescent light may look like lightning bolts. What seems normal to us can easily overwhelm any child with sensory issues, and this is especially true for a preemie whose brain and body are not yet able to handle the barrage of sensory input from the world.

Premature births occur now at record levels, largely due to increased numbers of multiple births from assisted reproduction. The March of Dimes reports that since the early

1980s, premature births have risen by 17 percent, and low birthweight has increased by 10 percent (March of Dimes, 1998). Most preemies are born between 32 and 37 weeks, although a small percentage are born "very preterm" at 31 weeks or less. As shown in the chart below, preemies are commonly grouped according to their weight.

Preemie Classifications

Normal birth weight:
5 ½ lbs. +

Low birth weight (LBW)
3 lbs., 5 oz. - 5 ½ lbs.

Very Low birth weight (VLBW)
2 lbs., 3 oz. - 3 lbs., 5 oz.

Extremely low birth weight (ELBW)
< 2 lbs., 3 oz.

Micro-preemie
< 1 lb., 11 oz.

Continued on page 12

Parenting Your Premie

(Continued from page 3)

With medical and technological advances such as artificial lung surfactant that coats immature lungs to improve respiratory function, greater numbers of quite young and small premies survive today. Over 90 percent of VLBW infants survive, as do 80 percent of ELBW, and 50 percent of micropremies.

Yes, they survive, but they start their lives with fragile nervous systems and a variety of medical complications. These babies, especially the youngest and smallest, are at high risk for a host of neurodevelopmental problems, including sensory and regulatory issues.

disorganized nervous system hasn't yet been fully insulated with myelin. So his body systems and "wiring" simply aren't ready to handle the onslaught of sensory messages from the busy world.

Think of sensory integration as an orchestra. The senses are like instruments. You need the woodwinds section, the strings section, the percussion, and the piano to all be in tune, playing in key at the right volume, all perfectly coordinated with one another. When a child is born prematurely, the music isn't controlled and coordinated. Different sections in the orchestra

sensitive premie, despite the efforts of the NICU primary care team, which typically includes neonatal nurses and occupational, physical, and respiratory therapists.

Most parents are stunned by how many medical procedures their premie undergoes in the NICU, including IV lines in arms, legs, and scalp, umbilical catheters, feeding tubes, blood sticks, and bright phototherapy (wearing goggles) to decrease bilirubin levels, to name just a few. Though they may be lifesaving, such painful procedures are an integral of the infant's first sensory experiences, and often underlie what later manifest as sensory defensiveness.

Most new parents require extra help to learn how to give their premature baby the sensory nourishment needed for optimal development, while taking special care not to overload the baby's delicate nervous system. Usually, moms and dads are sent home with warnings to look for signs of sensory and regulatory issues and developmental delays in their babies.

In addition to increased susceptibility to illness and other medical issues, premature infants tend to:

- Be highly sensitive to noise, light, touch, and movement
- Retain startle reflexes longer than expected
- Have muscles that are stiff, floppy, or a mix of both (abnormal muscle tone often resolves itself by 12–18 months)
- Be distractible and highly active or, conversely, be extremely quiet and sleep more than expected

Many NICUs have a neonatal follow-up clinic and/or refer parents to a local early intervention program.

Why Premies Are at Increased Risk

In the womb, a baby spends his time curled up, cozy and warm in the dark, listening to his mother's rhythmic heartbeat and muted sounds from the outside world. Meanwhile, his nervous system is developing at an astonishing speed, forming thousands upon thousands of essential nerve cell connections.

When a baby is born prematurely, his organ systems may not be ready to function outside of the mother's body, and his immature,

are out of tune and out of tempo, so nothing sounds quite right.

Most neonatal intensive care units (NICUs) do their very best to minimize overwhelming stimulation for a premie who typically spends her first days and weeks on a warming table for temperature regulation. Then, once stabilized, she rests in an Isolette (the incubator brand name that's nearly as synonymous with its function as a Band-Aid). Inevitable beeping and buzzing equipment, bright lighting, and bustling atmosphere can agitate a

- Have increased risk for vision and hearing problems
- Show delayed speech and language skills
- Develop oral defensiveness (because of negative oral experiences with feeding tubes, respirators and suctioning), which can interfere with feeding, as can abnormal muscle tone inside the mouth

Parenting with Sensory Smarts

Many NICUs have a neonatal follow-up clinic and/or refer parents to a local early intervention program. Early intervention services can be essential in managing all the physical and emotional challenges of caring for a premature baby, spurring development so that the baby can bridge the gap between chronological and adjusted age. “Adjusted age,” a term typically used for the first two years, is the age the baby would be if born at the end of a full-term, 40-week pregnancy. When parents and other caregivers develop and use “sensory smarts,” most, but not always all, sensory-based difficulties resolve as the baby’s nervous system matures, usually by around two years of age.

While all newborns fuss and cry when they are hungry, wet, cold, hot, or simply uncomfortable, preemies fuss and cry more than typical babies. Most preemies are quickly overstimulated by noise, visuals, handling, and other sensory experiences because their delicate systems are exquisitely sensitive and easily stressed. What’s more, once they are overloaded, their immature parasympathetic nervous systems

may take longer to help them relax and reorganize.

It is important that a new parent tune in quickly to what overwhelms her baby and learn to read the cues *before* he overloads. Signs of infant stress include:

- Increased heart and respiratory rate
- Changes in skin color, e.g., mottling
- Hiccups or sudden yawning
- Back arching
- Finger splaying
- Startle responses
- Excessive fussing and crying
- Shutting down, tuning out, and falling asleep

Calming Your Baby

A new mother may feel she is doing something wrong when her attempts to cuddle or sing to her baby distress rather than calm him. A new father may be mystified as to why every other dad can quiet his baby by carrying her around in his arms or in the stroller. Certainly, many infants are soothed by rocking, bouncing, walking, or singing a lullaby, but this is not necessarily so for an oversensitive preemie. Most often, a *reduction* in stimulation is called for. A parent may need to turn off music or TV, stop talking, dim the lights, and hold the baby, using sustained, unchanging tactile input such as holding him without patting his back and avoiding all unnecessary movement.

Most new parents of preemies need guidance on the best ways to touch and handle their baby. Research shows that Kangaroo Care, in which a newborn is nestled on her tummy on a parent’s bare chest

with one ear right by the parent’s heart, reduces stress, regulates body temperature and blood oxygen levels, and more. Firm touch via swaddling and whole-hand touch is more reassuring than light touch via fingertips. Infant massage is especially therapeutic for premature babies, providing muscular relaxation; relief from stress and painful conditions, such as colic; improved circulation; stimulation of digestion (there is a high correlation between massage and weight gain in preemies); and emotional bonding. Parents should learn how to provide infant massage themselves rather than have a practitioner do it. (And certainly make an appointment with a licensed massage therapist to give *you* a great massage!) For more information about infant massage and to find a local trainer, go to infantmassageusa.org.

Smell, especially that of mom’s skin and clothing, has been proven to calm premature infants. One study found that a pleasant odor (vanillin) reduced sleep apnea in the NICU when traditional medical interventions such as caffeine were ineffective. A new parent may want to explore which scents her baby will find most calming at home. A good scent to start with is therapeutic grade vanilla oil with very high vanillin content. Use a high quality essential oil in a diffuser (go to your local health food store or look online) rather than synthetic blends found in most body product chain stores. To be on the safe side, avoid shampoos, soaps, and body lotions containing lavender and tea tree oil. Recent studies indicate that these may cause hormonal imbalances in

young boys. (No effect has been reported in young girls.)

Regulating sleep patterns can be quite challenging. While some preemies do spend a lot of time sleeping, their sleep cycles tend to be short, with frequent awakenings. Kangarooing or carrying the baby in a sling, swaddling in the crib, and keeping feedings “low stim” (dim lights, no talking or playing), can help to regulate sleep-wake cycles. Since most preemies are hypersensitive, ambient noise as innocuous as a humming refrigerator can be upsetting. Add sound-dampening fabrics, and, if you cannot keep the crib far away from windows over busy streets, use double-glazed windows. Launder all bedding with extremely mild, scent-free detergent and softeners.

Feedings are often problematic. A preemie may have not yet mastered the suck-swallow-breathe sequence. He may have oral defensiveness or oral-motor problems, such as low muscle tone in the lips or tongue. Or he may simply be too distracted by other sensory stimuli. Preemies usually begin to feed from bottle or breast between 32 to 34 weeks as they develop muscle strength and energy. Most preemies are bottlefed. A variety of nipples is available, from the soft red preemie nipple to more typical newborn nipples. A parent may need to experiment to find the best one with the right flow rate.

During feeding, it's best for your baby to be in a flexed position, but take care that her torso is not hunched over because this makes it harder to breathe. Avoid conflicting input such as eye contact, talking, singing, and rocking while your baby is working hard to feed herself.

Household temperature should be around 68–72 degrees.

Other Tips for Preemie Parents

- Reduce overwhelming visual stimulation, including bright colors, patterns, toys, and decorations in the bedroom. An “interesting” crib or carriage mobile may not be a good idea yet.
- Keep your baby swaddled for a good part of the day, but always make sure his hands are free so he can suck on his fingers and fists. Make sure he has an opportunity during each day to kick and stretch his little legs too.
- When holding your baby, tuck in his arms and legs so that he is in a secure, flexed position.
- Because a preemie usually doesn't have adequate insulating fat, she'll need help to stay warm. Household temperature should be around 68-72 degrees. She'll need to wear an extra layer of clothing and a soft cap in most weather. In very hot weather, she may not need the extra layer, but be sure to protect her against a chilling draft from a fan or air conditioner.

There are numerous books and websites dedicated to premature infants. Prematurity.org has an online support group, insightful articles, and links to preemie clothing and product sources. Premature-infant.com has an excellent list of online resources, including information on feeding and support groups. If you will be working with an occupational therapist, make sure she or he has solid experience working with premature infants. For a list of early intervention programs by state and more on sensory issues, please visit sensorysmarts.com.

Most premature children with sensory problems do overcome their issues, especially those with parents who develop “sensory smarts”—pulling in the best therapists and learning how to meet the unique needs of their amazing children. ♦

References

- Biel, L., & Peske, N. (2005). *Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Integration Issues*. New York: Penguin.
- Kessenich, M. (2003). “Developmental outcomes of premature, low birth weight, and medically fragile infants.” *NBIN*, 3(3), 80-87.
- Madden, S.L. (2000). *The Preemie Parents' Companion*. Boston: Harvard Common Press.
- March of Dimes (1998). Perinatal epidemiology research initiative, March of Dimes Research Annual Report. White Plains, NY: March of Dimes Birth Defects Foundation.
- Marlier, L., Gaugler, C., & Messer, J. (2005). “Olfactory stimulation prevents apnea in premature newborns.” *Pediatrics*, 115 (1), 83-88.
- Maroney, D. (2003). “Recognizing the potential effect of stress and trauma on premature infants in the NICU.” *Journal of Perinatology*, 23, 679-683.
- Lindsey Biel, OTR/L, is a pediatric occupational therapist based in New York City and the co-author of *Raising A Sensory Smart Child*, with a foreword by Temple Grandin. She has authored numerous articles in both professional and consumer publications and frequently lectures on sensory issues and other developmental concerns. For more information, visit www.sensorysmarts.com.