

ABM Protocols

ABM Clinical Protocol #16: Breastfeeding the Hypotonic Infant

JENNIFER THOMAS, KATHLEEN A. MARINELLI, MARGARET HENNESSY,
and THE ACADEMY OF BREASTFEEDING MEDICINE PROTOCOL COMMITTEE

A central goal of The Academy of Breastfeeding Medicine is the development of clinical protocols for managing common medical problems that may impact breastfeeding success. These protocols serve only as guidelines for the care of breastfeeding mothers and infants and do not delineate an exclusive course of treatment or serve as standards of medical care. Variations in treatment may be appropriate according to the needs of an individual patient.

GOAL

TO PROMOTE, SUPPORT, AND SUSTAIN breastfeeding in children with hypotonia.

DEFINITION

Hypotonia, a condition of diminished muscle tone, is also referred to as “floppy infant syndrome,” and may occur with or without muscle weakness. There are diverse etiologies including abnormalities of the central or peripheral nervous system, neuromuscular junction, or muscle; metabolic, endocrine, or nutritional disorders; connective tissue diseases; and chromosomal abnormalities. Perinatal hypoxia, hypotonic cerebral palsy, and nonspecific mental deficiency may all result in central hypotonia. There is also a condition referred to as benign congenital hypotonia, which is a diagnosis of exclusion, and improves or disappears entirely with age.¹ Preterm infants as well will have age appropriate hypotonia. Hypotonic babies often have feeding problems that result from abnormal or underdeveloped control of the oropharyngeal structures, contributing to an uncoordinated and/or weak suck.

BACKGROUND

One of the more common causes of hypotonia, which we shall use as an example, is Down syndrome. Down syndrome is a genetic disorder caused by a trisomy of chromosome 21 resulting in hypotonia in more than 90% of cases. Associated oral abnormalities characteristically include malocclusion and a small mouth with a relatively large, protruding tongue, which when coupled to the hypotonia, result in significant associated feeding difficulties in some, but not all, of these children.²

The Academy of Breastfeeding Medicine, American Academy of Pediatrics, World Health Organization, and other international organizations have recommended that all children should be breastfed, unless there is a medical contraindication.³ It is particularly important that Down syndrome and other hypotonic children be breastfed, to minimize the risk of morbidities associated with artificial feedings, many of which they are at increased risk from by virtue of their condition. For example, in addition to the oral abnormalities and malocclusion, children with Down syndrome also have developmental delay, are more susceptible to ear, respiratory, and other infections, and have

an increased incidence of other congenital anomalies such as heart and gastrointestinal malformations. In looking at the effects of breastfeeding on these problems in a healthy population, approximately 44% of dental malocclusion can be attributed to lack of or short duration of breastfeeding,⁴ suggesting that breastfeeding promotes oral motor strength, a potential benefit to those children with Down syndrome and other causes of hypotonia.² Breastfeeding helps with normal mouth and tongue coordination. Breastfeeding has also been shown to be protective against the development of ear and respiratory infections.⁴⁻⁸ Studies indicate that there is a positive neurocognitive advantage of breastfeeding,⁹⁻¹² which is most pronounced in low birth weight and small for gestational age children¹³⁻¹⁷ who may score as many as eight points higher on intelligence tests than their formula-fed counterparts. As hypotonic babies may have disorders associated with neurocognitive impairment, the benefit of human milk feedings could make an important difference to their long-term outcome. Children with congenital heart disease who breastfeed have better growth, shorter hospital stays, and higher oxygen saturations than children with congenital heart disease that are formula fed.¹⁸ Again, this may suggest potential benefit to hypotonic infants with heart disease, seen in a significant proportion of babies with Down syndrome. Thus, although children with Down syndrome and other forms of hypotonia have not been specifically studied, based on the wealth of information available from studies in the general population, they may be expected to benefit from breastfeeding and/or expressed breastmilk.

Some mothers of children with Down syndrome express anxiety and fear at the time of their child's diagnosis. Many express feeling "helpless"¹⁹ or frustrated that they were not able to breastfeed, or felt as if they were not given support for breastfeeding.²⁰ The ability to breastfeed their babies may empower these mothers.

Challenges to breastfeeding the hypotonic child exist, but many can successfully feed at the breast. No evidence exists that Down syndrome or other hypotonic infants feed better with the bottle than at the breast.²¹ Further, no

evidence suggests that these children need to feed from a bottle before going to breast.¹⁶ Breastfeeding should be actively promoted and supported in these infants.

Sucking behavior, specifically in Down syndrome, has been documented to be less efficient than in normal-term infants with multiple parameters affected, including sucking pressure, frequency, and duration, as well as a deficiency in the smooth peristaltic tongue movement.²² When followed longitudinally over the first year, sucking pressure increased significantly by 4 months and again by 8 months. Frequency increased by 4 months. Duration did not increase over time, and peristalsis only normalized in the minority of infants who were restudied at 8 months. However, the overall result was improvement in sucking efficiency over the first year. Mothers tended to report that feeding problems were substantially improved by 3-4 months of age. Understanding this time frame allows practitioners to effectively support these mothers and babies to improve breastfeeding skills, and reach and maintain a sufficient milk supply that may enable them to ultimately successfully breastfeed, even with the presence of significant difficulties at the beginning.

PROCEDURES

Education

1. All mothers should be educated about the benefits of breastfeeding for themselves and their infants. A significant percentage of hypotonic infants can feed at the breast without difficulty.
2. All babies should be followed closely both before and after discharge from the hospital for assessment of further needs.

Facilitation and assessment of feeding at the breast in the immediate postpartum period

1. The first feeding should be initiated as soon as the baby is stable. There is no reason this cannot occur as early as the delivery room if the baby is physiologically stable.
2. Kangaroo (skin-to-skin) care should be strongly encouraged. If the baby does not

feed well, the touching may be stimulating, so that the baby is easier to arouse for feedings. Skin-to-skin care has also been shown to help increase mother's milk supply,²³ and it can assist with bonding, which may be especially important for these families.

3. Assess the baby's ability to latch, suck, and transfer milk. This assessment should involve personnel specifically trained in breastfeeding evaluation and management.
4. Skin-to-skin contact will facilitate frequent attempts at breast. For those attempts, particular attention should be given to providing good head and body support since the baby needs to spend effort sucking, not supporting body position. Use of a sling or pillows to support the infant in a flexed position allows the mother to use her hands to support both her breast and the infant's jaw simultaneously.
5. The "Dancer hand" position (see Fig. 1) may be helpful to the mother to try because it supports both her breast and her baby's chin and jaw while the baby is nursing. This involves cupping her breast in the palm of her hand (holding her breast from below), with the third, fourth, and fifth fingers curling up towards the side of her breast to support it, while simultaneously allowing the baby's chin to rest on the web space between her thumb and index finger (see Fig. 1). The thumb and index finger can then give gentle pressure to the masseter muscle, which stabilizes the jaw.^{24,25} Addi-



FIG. 1. Dancer hand position. (Original photograph by author (JT) used with permission.)

tionally, pulling the jaw slightly forward may allow the infant to better grasp the breast and form a seal. The other hand is free to be used to support the baby's neck and shoulders.

6. Other strategies to help the infant latch and transfer milk may also be effective. Some mothers facilitate milk transfer with the technique of breastfeeding used in conjunction with hand compression. Instead of placing the thumb and index finger on the baby's jaw for support (Dancer position), the fingers are kept proximal to the areola, and milk is hand expressed as the baby suckles. A thin silicon nipple shield may be useful, if production is generous (>500 mL/day) and mothers learn how to keep the reservoir filled by synchronizing breastfeeding with hand compression or using a nursing supplementation device simultaneously inside the shield.²⁶ By making the mother aware of various techniques, aids, and ideas, she is empowered to experiment and discover the best repertoire to fit her and her baby's individual needs.
7. The mother, and family who is supporting her, should be counseled that more time may be necessary in the early weeks to complete a feeding. They should also know that in many cases the baby's ability to feed will improve over the first weeks to months.
8. Trained personnel must reassess the baby frequently (a minimum of once every 8 hours) because these babies must be considered high (breastfeeding) risk, similarly to the near-term baby (see ABM Protocol #10 Breastfeeding the Near-Term Baby).²⁷ Encourage frequent nursing throughout the day as the ability to sustain suck may be impaired. Infants should go to breast as often as possible, aiming for at least 8 to 12 times per 24 hours. Prolonged periods of skin-to-skin contact will facilitate these frequent attempts at breast. Assessments should include state of hydration and jaundice, as possible complications of poor intake.
9. Once transitional milk is present, test-weighing with an appropriate digital scale

may be an option to judge adequate milk transfer. Infants are weighed immediately prior to the feed on an electronic scale with accuracy at minimum ± 5 g, and then reweighed immediately after the feed with the exact same diaper, clothing, blankets, etc. worn during the prefeed weight. Intake during the feed is reflected by weight gain, 1 g = 1 mL. Term infants with Down syndrome gain weight more slowly than normal full-term infants,²⁸ so this must be taken into consideration during the early weeks and months. Growth charts specific for Down syndrome are found at <http://www.growthcharts.com/charts/DS/charts.htm> (last accessed Jan 21, 2007).

10. Consider alternative modes of feeding if the baby is unable to nurse at the breast or sustain adequate suckling, including the use of a cup,²⁹ a spoon, or a wide-based silicone bottle. The use of a nursing supplementation aid alone (without a nipple shield—Section B6) may not be as helpful, as it works best with a baby who has an effective latch, the lack of which is often one of the significant problems of hypotonic infants.
11. If supplementation is necessary, please see Academy of Breastfeeding Medicine Protocol #3 (Hospital Guidelines for the Use of Supplementary Feedings in the Healthy Term Breastfed Infant).³⁰ If the baby is attempting to suckle, following each breastfeeding encounter with breastmilk expression (see below), followed by spoon or cup feeding of the expressed milk to the baby, provides more stimulation to the breasts and more milk to the baby.

Preventative measures to protect a milk supply

1. If the infant is unable to successfully and fully breastfeed, or if the mother is separated from her infant (e.g., neonatal intensive care unit admission), lactation must be initiated and/or maintained through pumping or hand expression. Anticipating the initial difficulty an hypotonic infant will likely have with sustaining frequent and effective milk removal, insufficient milk production may be prevented by encouraging mothers to ex-

press milk shortly after delivery, ideally within 2 hours (certainly within the first 6 hours as is recommended with preterm mothers),³¹ and approximately every 3 hours thereafter. Aim to remove milk at least eight times in a 24-hour period, mimicking the stimulation of a vigorous term breastfeeding baby. Even if the baby shows some ability to go to breast, latch, and transfer milk, the mother will likely need to express or pump extra milk in the early weeks in order to build and maintain her milk supply at the higher level. A plentiful milk supply will enhance letdown for these less vigorous babies, and facilitate their feeding effort.

2. Most of the research on initiating and maintaining milk supply by expressing milk has been done on mothers of preterm infants. The strongest determinant of duration and exclusivity of breastfeeding the preterm infant is the volume of milk produced by the pump-dependent mother, while insufficient milk production is the most common reason for cessation of efforts to provide milk for these infants.^{32–34} As the baby begins to improve with milk transfer, developing rhythms, and showing feeding cues, pumping times can be led by these cues (i.e., breast emptying by expression after each attempt at breast). This pattern should continue until the couplet is reunited and/or the infant is able to sustain successful breastfeeding. It is critical that mothers be instructed on effective pumping, including both the use of a hospital grade electric pump if available and manual expression.
3. Extrapolating from preterm research for guidance in the hypotonic baby, the production of 500 mL/day is commonly cited as the minimum volume enabling premature babies <1500 grams to transition from tube or bottle feeding to successful, exclusive breastfeeding.³⁵ Until studies are done in the hypotonic infant population, this is a minimum volume from which to start, and can be adjusted based on calculations of intake necessary for growth.
4. Simultaneous pumping of both breasts with a hospital-grade pump has been shown to be more effective than single pumping. Recent research suggests manually assisted

pumping improves effective emptying and production in pump-dependent women. In contrast to the usual practice of passively depending on the pump to suction milk from the breast, manual techniques, used in conjunction with pumping, enable mothers to enhance emptying by using their hands for breast compression, massage, and expression.³⁶

5. A pumping/feeding diary or log, to enable health care providers to track maternal milk supply and intervene when needed, can consist simply of a piece of paper with columns for date, time started pumping, time ended pumping, amount of milk expressed, and comments (such as where pumped, unusual stressors, etc.), or can be ordered or used as a model from various Web sites, including: <http://www.cpqcc.org/Documents/NutritionToolkit/NutritionToolkit.pdf>, appendix "O" (last accessed January 21, 2007).

At discharge and in the neonatal period

1. If the baby will remain hospitalized, the mother's milk supply should be assessed daily including pumping frequency, 24-hour milk total, and any signs of breast discomfort. Carefully monitor the baby's weight gain and consider supplementation as necessary.
2. Inform mothers that sucking efficiency frequently continues to improve over the first year, such that the breastfeeding experience may "normalize" and may not continue to require interventions initially necessary for their own infant, for example, supplementation, pumping, more frequent nursing, etc.
3. Provide information about local support groups for breastfeeding and for specific diagnoses such as Down syndrome families. Support and encouragement is particularly important for these mothers and families with the additional patience and time that is sometimes required to breastfeed these infants.
4. Maternal milk supply is affected by ineffective or infrequent pumping/expressing. Although stress, fatigue, and pain are frequently cited as determinants of slow milk

supply, recent evidence refutes this.³⁷ However, it is not unreasonable to encourage maternal rest and analgesics as needed. Review and optimize breastmilk expression frequency, schedule, and type of pump used, if necessary. A pumping diary/log (see earlier) can be useful.

5. If maternal milk supply does not equal or exceed the infant's needs, or begins to slow despite optimal pumping, the use of galactagogues to enhance maternal milk supply may be considered. Please see Academy of Breastfeeding Medicine Protocol #9 (Use of Galactagogues in Initiating or Augmenting Maternal Milk Supply).³⁸
6. In the presence of significant cardiac, gastrointestinal, or renal complications, it is sometimes necessary to increase the caloric density of breastmilk with extra fat, carbohydrate, or protein. If the mother's milk supply is greater than the baby's needs, a trial of feeding hindmilk (higher fat content, therefore more fat calories), either by expressing some of the foremilk before putting the baby to breast, or if supplements are being used, by pumping off a small volume of milk first (foremilk) and then in a separate container pumping the rest of the milk present (hindmilk) and feeding the baby only the hindmilk.

Further research

This protocol was developed for the Academy of Breastfeeding Medicine to give clinicians guidance based on the expert opinion of practitioners who have worked extensively with this population. There is little scientific evidence upon which to base recommendations. Specific areas recommended for further research include:

1. Methods of optimizing the hypotonic infant's suck and milk transfer need further study.
2. Use of pacifiers in premature infants as "practice" oral feeding during gavage feeds has assisted with the transition to breast, and merits evaluation in hypotonic infants.³⁹
3. Comparison of autonomic stability between breast and bottle fed infants with Down syn-

drome or other etiologies of hypotonia may be helpful.

4. Evaluation of weight gain in breastfed versus formula fed hypotonic infants, once breastfeeding has been established.
5. Evaluation of different methods available to supplement hypotonic babies (cup, bottle, spoon) to determine efficacy and best practice.
6. Modifiable factors which may compound or ameliorate the difficulties with breastfeeding in these infants in particular, for example, labor analgesia/anesthesia, skin-to-skin contact perinatally, etc.

ACKNOWLEDGMENT

This work was supported in part by a grant from the Maternal and Child Health Bureau, Department of Health and Human Services.

REFERENCES

1. Rudolph CD, Rudolph AM, Hostetter MK, et al., eds. (2003). *Rudolph's Pediatrics*. 21st ed. McGraw-Hill, New York.
2. Aumonier ME, Cunningham CC. Breast feeding in infants with Down's syndrome. *Child Care Health Dev* 1983;9:247-255.
3. American Academy of Pediatrics. Section on Breastfeeding. Breastfeeding and the Use of Human Milk. *Pediatrics* 2005;115:496-506.
4. Labbok M, Hendershot G. Does breastfeeding protect against malocclusion? An analysis of the 1981 child health supplement to the national health interview survey. *Am J Prev Med* 1987;3:227-232.
5. Saarinen UM. Prolonged breast feeding as prophylaxis for recurrent otitis media. *Acta Paediatr Scand* 1982;71:567-571.
6. Owen MJ, Baldwin CD, Swank PR, et al. Relation of infant feeding practices, cigarette smoke exposure, and group child care to the onset and duration of otitis media with effusion in the first two years of life. *J Pediatr* 1993;123:702-711.
7. Oddy WH, Sly PD, de Klerk NH, et al. Breast feeding and respiratory morbidity in infancy: A birth cohort study. *Arch Dis Child* 2003;88:224-228.
8. Duncan B, Ey J, Holberg CJ. Exclusive breast-feeding for at least 4 months protects against otitis media. *Pediatrics* 1993;91:867-872.
9. Aniansson G, Alm B, Andersson B, et al. A prospective cohort study on breast-feeding and otitis media in Swedish infants. *Pediatr Infect Dis J* 1994;13:183-188.
10. Anderson JW, Johnstone BM, Remley DT. Breast-feeding and cognitive development: A meta-analysis. *Am J Clin Nutr* 1999;70:525-535.
11. Horwood LJ, Fergusson DM. Breastfeeding and later cognitive and academic outcomes. *Pediatrics* 1998;101:E9.
12. Jacobson SW, Chiodo LM, Jacobson JL. Breastfeeding effects on intelligence quotient in 4- and 11-year-old children. *Pediatrics* 1999;103:E71.
13. Vohr BR, Poindexter BB, Dusick AM, et al. Beneficial effects of breastmilk in the neonatal intensive care unit on the developmental outcomes of extremely low birth weight infants at 18 months of age. *Pediatrics* 2006;118:e115-e123.
14. Mortensen EL, Michaelsen KF, Sanders SA, Reinisch JM. The association between duration of breastfeeding and adult intelligence. *JAMA* 2002;287:2365-2371.
15. Rao MR, Hediger ML, Levine RJ, et al. Effect of breastfeeding on cognitive development of infants born small for gestational age. *Acta Paediatr* 2002;91:267-274.
16. Anderson JW, Johnstone BM, Remley DT. Breast-feeding and cognitive development: A meta-analysis. *Am J Clin Nutr* 1999; 70:525-535.
17. Slykerman RF, Thompson JM, Becroft DM, et al. Breastfeeding and intelligence of preschool children. *Acta Paediatr* 2005;94:832-837.
18. Marino BL, O'Brien P, LoRe H. Oxygen saturation during breast and bottle feeding in infants with congenital heart disease. *J Pediatr Nurs* 1995;10:360-364.
19. Skotko, B. Mothers of children with Down Syndrome reflect on their postnatal support. *Pediatrics* 2005;115:64-77.
20. Pisacane A, Toscano E, Pirri I, et al. Down syndrome and breastfeeding. *Acta Paediatr* 2003;92:1479-1481.
21. Lawrence R, Lawrence R. *Breastfeeding: A Guide for the Medical Profession*. 6th ed. Mosby, St. Louis, 2005.
22. Mizuno K, Ueda A. Development of sucking behavior in infants with Down's syndrome. *Acta Paediatr* 2001;90:1384-1388.
23. Hurst NM, Valentine CJ, Renfro L, et al. Skin to skin holding in the neonatal intensive care unit influences maternal milk volume. *J Perinatol* 1997;17:213-217.
24. McBride MC, Danner SC. Sucking disorders in neurologically impaired infants: assessment and facilitation of breastfeeding. *Clin Perinatol* 1987;14:109-130.
25. Danner, SC. Breastfeeding the neurologically impaired infant. *Perin Womens Health Nurs* 1992;3:640-646.
26. Meier PP, Brown LP, Hurst NM, et al. Nipple shields for preterm infants: Effects on milk transfer and duration of breastfeeding. *J Hum Lact* 2000;16:106-114.
27. Boies E, Vaucher Y, Protocol Committee Academy of Breastfeeding Medicine. Clinical Protocol Number 10: Breastfeeding the near-term infant (35-37 weeks). 2004. Academy of Breastfeeding Medicine. Accessed January 21, 2007 from www.bfmed.org.
28. Crong C, Crocker AC, Puessel SM. Growth charts for children with Down syndrome: 1 month to 18 years of age. *Pediatrics* 1988;81:102-110.

29. Marinelli K, Burke G, Dodd V. A comparison of the safety of cup feedings and bottle feedings in premature infants whose mothers intend to breastfeed. *J Perinatol* 2001;21:350–355.
30. Protocol Committee Academy of Breastfeeding Medicine. Clinical Protocol Number 3: Hospital guidelines for the use of supplementary feedings in the healthy term breastfed infant. 2002. Academy of Breastfeeding Medicine. Accessed January 21, 2007 from www.bfmed.org.
31. Hill PD, Brown LP, Harker TL. Initiation and frequency of breast expression in breastfeeding mothers of LBW and VLBW infants. *Nurs Res* 1995;44:353–355.
32. Sisk PM, Lovelady CA, Dillard RG, Gruber KJ. Lactation counseling for mothers of very low birth weight infants: Effect on maternal anxiety and infant intake of human milk. *Pediatrics* 2006;117:e67–e75.
33. Killersreiter B, Grimmer I, Buhner C, et al. Early cessation of breastmilk feedings in very low birth weight infants. *Early Hum Dev* 2001;60:193–205.
34. Furman L, Minich N, Hack M. Correlates of lactation in mothers of very low birth weight infants. *Pediatrics* 2002;109:e57.
35. Meier PP. Supporting lactation in mothers with very low birth weight infants. *Pediatr Ann* 2003;32:317–325.
36. Jones E, Dimmock PW, Spencer SA. A randomized controlled trial to compare methods of milk expression after preterm delivery. *Arch Dis Child Fetal Neonat Ed* 2001;85:F91–F95.
37. Hill PD, Aldag JC, Chatterton RT, Zinaman M. Psychological distress and milk volume in lactating mothers. *West J Nurs Res* 2005;27:676–693.
38. Montgomery A, Wight N, Protocol Committee Academy of Breastfeeding Medicine. Clinical Protocol Number 9: Use of galactagogues in initiating or maintaining maternal milk supply. 2004. Academy of Breastfeeding Medicine. Accessed January 21, 2007 from www.bfmed.org.
39. McCain GC, Gartside PS, Greenberg JM, Lott JW. A feeding protocol for healthy preterm infants that shortens time to oral feeding. *J Pediatr* 2001;139:374–379.

Contributors

*Jennifer Thomas, M.D.

Department of Family Medicine and Pediatrics
 Medical College of Wisconsin
 Wheaton Franciscan Healthcare—All Saints
 Medical Group
 Racine, WI

*Kathleen A. Marinelli, M.D.

Pediatrics, University of Connecticut School of
 Medicine
 Connecticut Children's Medical Center
 Hartford, CT

Margaret Hennessy, M.D.

Wheaton Franciscan Healthcare—All Saints
 Medical Group
 Racine, WI

Protocol Committee

Caroline J. Chantry M.D., Co-Chairperson

Cynthia R. Howard, M.D., MPH,
 Co-Chairperson

Ruth A. Lawrence, M.D.

Kathleen A. Marinelli, M.D., Co-Chairperson

Nancy G. Powers, M.D., FABM

*Lead authors.

For reprint requests: abm@bfmed.org