

## ABM Clinical Protocol #16: Breastfeeding the Hypotonic Infant, Revision 2016

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*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

**T**O PROMOTE, SUPPORT, and sustain breastfeeding in infants and young children with hypotonia.

### Definition

Muscle tone, the muscle's resistance to passive stretch during resting state, is distinct from muscle strength and can be affected by many factors. Hypotonia, a condition of diminished muscle tone, may occur with or without muscle weakness. There are diverse etiologies including abnormalities of the central or peripheral nervous systems; neuromuscular junction; muscle, metabolic, endocrine, or nutritional disorders; connective tissue diseases; and chromosomal abnormalities. Perinatal hypoxia and hypotonic cerebral palsy may result in central hypotonia. In addition, benign congenital hypotonia, a diagnosis of exclusion, improves or disappears entirely with age.<sup>1</sup>

### Background

Hypotonic infants often have breastfeeding problems that result from abnormal or underdeveloped control of the oropharyngeal structures, contributing to an uncoordinated and/or weak suck, similar to those experienced by premature infants. Despite the many etiologies for hypotonia, little research has been specifically undertaken on the feeding problems of the hypotonic infant. However, interventions used for infants with important causes of hypotonia, such as Trisomy 21 (Down syndrome) and prematurity, can be applied to the care of these infants.

Trisomy 21, a genetic disorder where more than 90% of infants have hypotonia, shares many of the same feeding risks and complicating morbidities as other causes of hypotonia. Associated oral abnormalities characteristically include

malocclusion and a small mouth with a relatively large protruding tongue, which when coupled with hypotonia result in significant feeding difficulties in some of these children.<sup>2</sup>

In many countries premature infants, who may also have hypotonia-related difficulties, are often separated from their mothers shortly after birth, which can increase breastfeeding difficulties. Premature infants also struggle with small and underdeveloped oral structures and difficulties with suck-swallow coordination.<sup>3</sup>

The Academy of Breastfeeding Medicine, the American Academy of Pediatrics, the World Health Organization, and other international organizations recommend that all infants should be breastfed unless there is a medical contraindication.<sup>4,5</sup> It is particularly important that infants and young children with hypotonia, including those with Trisomy 21, be breastfed because of their increased risk of morbidities associated with artificial feeding. For example, children with Trisomy 21 are more susceptible to ear, respiratory, and other infections, have developmental delay, and an increased incidence of other congenital anomalies such as heart and gastrointestinal malformations in addition to oral abnormalities and malocclusion.

A systematic review examining the effects of breastfeeding on these problems in a healthy population found that breastfeeding is protective against the development of ear and respiratory infections.<sup>6,7</sup> It is also associated with a significantly lower risk of malocclusion (odds ratio 0.34; 95% confidence interval 0.24–0.48),<sup>8</sup> which suggests that breastfeeding promotes oral motor strength, and, therefore, has potential benefit to children with Trisomy 21 and other causes of hypotonia.<sup>2</sup> Breastfeeding helps with normal mouth and tongue coordination.

Studies indicate that there is a positive neurocognitive advantage of breastfeeding,<sup>6,9</sup> which is most pronounced in children with low birth weight or who were small for

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gestational age.<sup>10</sup> As hypotonic infants may have disorders associated with neurocognitive impairment, this advantage of human milk over infant formula 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 who are formula fed.<sup>11</sup> Again, these findings suggest a potential advantage for breastfeeding hypotonic infants with congenital heart disease, such as can occur in infants with Trisomy 21. Thus, although children with hypotonia have not been specifically studied, based on information from studies in the general population, they would be expected to benefit from breastfeeding and/or being fed expressed human milk.

Sucking behavior in hypotonic infants, specifically those with Trisomy 21, is less efficient than in normal term infants with multiple parameters affected, including the pressure, frequency, and duration of sucking and smooth peristaltic tongue movement.<sup>12</sup> (II-2) (Quality of evidence [Levels of evidence I, II-1, II-2, II-3, and III] is based on the U.S. Preventive Services<sup>13</sup> Task Force Appendix A Task Force Ratings and is noted in parentheses.) When followed longitudinally over the first year, sucking pressure increased significantly by 4 months and again by 8 months and sucking frequency increased by 4 months. Sucking 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 an improvement in sucking efficiency over the first year.

Mothers tended to report that feeding problems improved substantially by 3–4 months of age. Understanding this time frame allows practitioners to effectively support mothers and their hypotonic infants to improve breastfeeding skills and reach and maintain a sufficient milk supply that may enable them to successfully breastfeed, despite the presence of significant difficulties at the beginning.

Breastfeeding the hypotonic infant is challenging, but many can successfully feed at the breast. There is no evidence that infants with Trisomy 21 or other hypotonic infants feed better with the bottle than at the breast and no evidence suggests that these children need to feed from a bottle before attempting to breastfeed.

Whenever possible, a team of professionals with expertise in assisting infants with special needs to breastfeed should work together to help the mother–infant dyad. The importance of knowledgeable health professionals is highlighted in studies that found some mothers of children with Trisomy 21 felt they were not given important support for breastfeeding. Instead, they expressed feeling “helpless,”<sup>14</sup> or were frustrated that they were not able to meet their breastfeeding goals. Had these mothers received support that enabled them to breastfeed their infants, they would likely have felt empowered rather than discouraged or frustrated.

## Procedures

### A. Prenatal care:

1. Healthcare providers should encourage all mothers to breastfeed, whether the infant has a high risk of hypotonia or not. Encouragement can make a significant difference as to whether a mother decides to breastfeed or not.<sup>15,16</sup> (II-2, II-2)

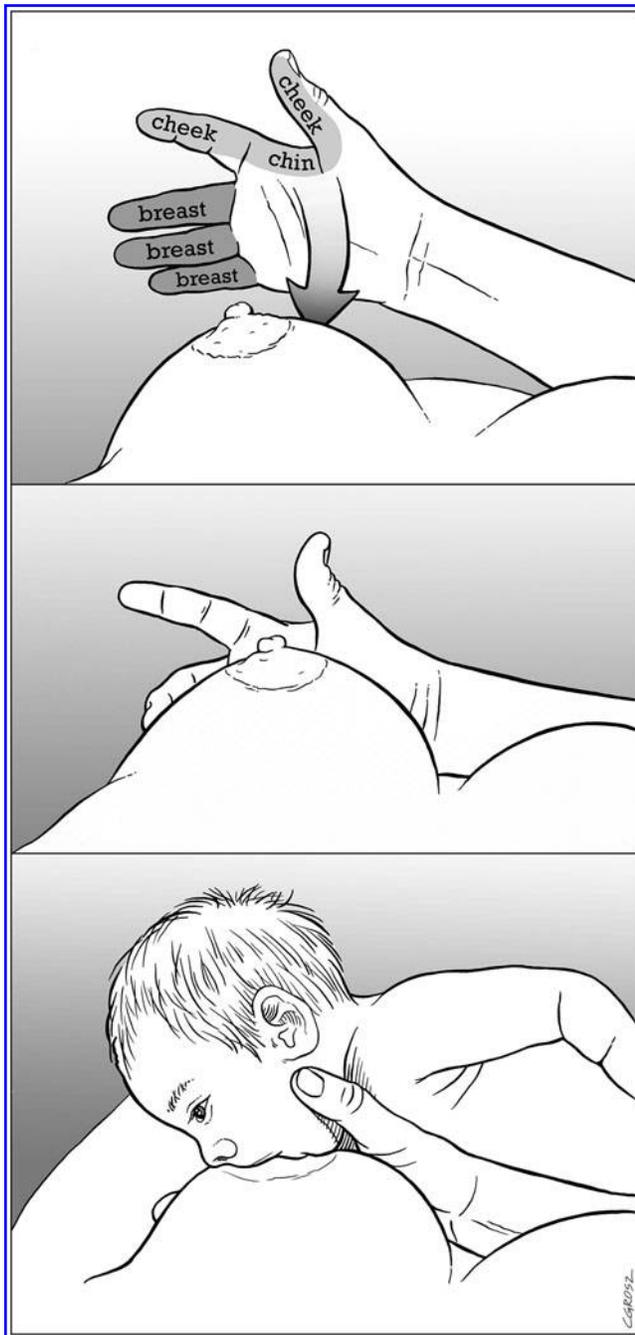
2. A breastfeeding history should be obtained as part of prenatal care, and identified concerns and risk factors for breastfeeding difficulties should be communicated to the infant’s healthcare provider(s).<sup>17</sup> (III)
3. If it is known during pregnancy that the infant will have hypotonia, mothers should be referred to breastfeeding medicine specialists and/or lactation consultants with expertise with hypotonic infants.

### B. Education:

1. All mothers should be educated about the advantages for themselves and their infants of breastfeeding and of providing human milk. A significant proportion of hypotonic infants can feed at the breast without difficulty.
2. Infants with hypotonia should be followed closely both before and after discharge from the hospital to assess further needs.

### C. Facilitation and assessment of feeding at the breast in the immediate postpartum period:

1. The first feed should be initiated as soon as the infant is stable. There is no reason this cannot occur early, for example, in the delivery room, if the infant is physiologically stable. Extra support and supervision may be required.
2. Kangaroo (skin-to-skin) care should be strongly encouraged. As with all infants, when infants with hypotonia are being held skin-to-skin, care should be taken to ensure the mother is fully awake and infant’s face is visible and airway remains open. If the infant does not feed well, the touching may be stimulating so that the infant is easier to arouse for feedings. Skin-to-skin care has also been shown to help increase mother’s milk supply,<sup>18,19</sup> (II-2, II-2) and, in addition to eye contact and touching, can assist with bonding that may be especially important for these families.
3. Assessment of the infant’s ability to latch, suck, and transfer milk should involve personnel specifically trained in breastfeeding evaluation and management.
4. For attempts at breastfeeding, particular attention should be given to providing good head and body support for the infant since he/she 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 (Dancer hand position). Skin-to-skin contact will facilitate frequent attempts at breast.
5. The “Dancer hand” position (Fig. 1) may be helpful for the mother to try as it supports both her breast and her infant’s chin and jaw while the infant is breastfeeding. The mother cups her breast in the palm of her hand (holding her breast from below), with the third, fourth, and fifth fingers curling up toward the side of her breast to support it, while simultaneously allowing the infant’s chin to rest on the web space between her thumb and index finger. The thumb and index finger can then



**FIG. 1.** Dancer hand position from the mother's view. Illustration by Claudia Grosz, MFA.

give gentle pressure to the masseter muscle, which stabilizes the jaw.<sup>20,21</sup> (II-2, II-2) In addition, pulling the jaw slightly forward may allow the infant to better grasp the breast and form a seal. The other hand is free to support the infant's neck and shoulders.

6. Other strategies to help the infant latch and transfer milk may also be effective. Some mothers facilitate milk transfer by using hand compression in conjunction with breastfeeding. Instead of placing the thumb and index finger on the infant's jaw for support (Dancer hand position), the fingers are kept

proximal to the areola, and milk is hand expressed as the infant suckles. A thin silicone nipple shield may be useful if milk 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.<sup>22</sup> (II-3)

By making the mother aware of various techniques, aids, and ideas, she can experiment and discover the best ways to fit her and her infant's individual needs.

7. More time may be necessary in the early weeks to complete a feeding. Mothers, and the family that supports them, should also know that in many cases the infant's ability to feed will improve over the first weeks to months.
8. Trained personnel should reassess the infant frequently (a minimum of once every 8 hours) as these infants must be considered at high risk of breastfeeding difficulties, similar to the late preterm infant (see ABM Protocol #10: Breastfeeding the Late Preterm Infant).<sup>23</sup> Encourage frequent breastfeeding 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.<sup>5</sup> Prolonged periods of skin-to-skin contact will facilitate these frequent attempts at breast. Assessments should include state of hydration and jaundice to identify possible complications of poor oral intake.
9. Once transitional milk is present, test weighing with an appropriate digital scale may be an option to assess adequate milk transfer for these infants. Infants are weighed immediately before the feed on an electronic scale with accuracy at minimum  $\pm 5$  g, and then reweighed immediately after the feed under the exact same circumstances: diaper (nappy), clothing, blankets, etc. Intake during the breastfeed is reflected by weight gain,  $1 \text{ g} = 1 \text{ mL}$ . Infants with Trisomy 21 may gain weight more slowly than normal full-term infants.<sup>24</sup> (II-3) New growth charts for infants with Trisomy 21, introduced in 2015, are designed to more accurately reflect normal growth for these infants.<sup>24</sup>
10. Consider alternative modes of feeding such as a cup,<sup>25</sup> (I) spoon, or syringe, if the infant is unable to breastfeed or sustain adequate suckling. The use of a nursing supplementation aid alone (without a nipple shield—see C6) may not be as helpful, as it works best with an infant who has an effective latch and infants with hypotonia often have difficulties with latch.
11. If supplementation is necessary, see Academy of Breastfeeding Medicine Protocol #3 (Hospital Guidelines for the Use of Supplementary Feedings in the Healthy Term Breastfed Infant).<sup>26</sup> If the infant is attempting to suckle, follow each breastfeeding encounter with breastmilk expression (see D) and then feed expressed milk to the infant by spoon, cup, or other device. This provides more stimulation to the breasts and more milk to the infant.

12. At times, some of these infants may have issues with dysphagia and aspiration of feedings of any type. There is some evidence that thickening of feedings in these circumstances can decrease the risks. Close communication with the team managing these feeds is crucial for the breastfeeding mother who will be providing breastmilk to be used with the thickening substance.<sup>27,28</sup> (I, III)

#### D. Preventive 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., NICU admission), lactation should be initiated and/or maintained through milk expression by hand or pump. Mothers should be encouraged to express milk shortly after the birth, ideally within the first hour,<sup>29</sup> (I) and approximately every 3 hours thereafter. Older recommendations suggested expressing within the first 6 hours of birth.<sup>50</sup> (II-3) The mother should aim to remove milk at least eight times in a 24 hour period, mimicking the stimulation of a vigorous term breastfeeding infant. Even if the infant shows some ability to go to breast, latch, and transfer milk, the mother will benefit from expressing extra milk in the early weeks to build and maintain her milk supply.
2. Most of the research on initiating and maintaining milk supply by expressing milk has been conducted 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, whereas insufficient milk production is the most common reason for cessation of efforts to provide milk for these infants.<sup>30-32</sup> (II-3, II-3)

As milk transfer begins to improve with the infant developing sucking rhythms, and showing feeding cues, expressing can be tailored to these signs (i.e., breast emptying by expression after each attempt at breast). This pattern should continue until the dyad is reunited and/or the infant is able to sustain full breastfeeding. It is critical that mothers be instructed on effective milk removal, including expressing with the use of a hospital-grade electric pump, if available, and hand expression. Combining mechanical pumping and hand expression can increase both milk volume<sup>33</sup> (III) and the caloric content.<sup>34</sup> (I)

3. Extrapolating from preterm research for guidance in feeding the hypotonic infant, breastmilk production of 500 mL/day is commonly cited as the minimum volume enabling premature infants of less than 1,500 g to transition from tube or bottle feeding to successful, exclusive breastfeeding.<sup>35</sup> (III) Until studies are done in infants with hypotonia, this is a minimum volume from which mothers can start to reduce any supplementation and can be adjusted based on calculations of intake necessary for growth.
4. When an electric breast pump is used, simultaneous expression of both breasts with a hospital-grade pump is more effective than single breast expression. Hand expression while pumping improves expressed milk volume and milk caloric content in

pump-dependent women. Thus, in contrast to the usual practice of passively depending on the pump to remove milk from the breast, hand expression, massage, and compression, used in conjunction with mechanical expression, enable mothers to enhance breast emptying.<sup>33,36,37</sup> (II-2, I)

5. Mothers should consider keeping an accurate expressing/feeding log to enable her and her health-care providers to track milk supply and intervene if there is concern about milk volume.<sup>38</sup> (III)

#### E. At discharge and in the neonatal period:

1. If the infant remains hospitalized, the mother's milk supply should be assessed daily. That assessment should include time at the breast, expression frequency, 24 hour milk total by expression, and any signs of breast discomfort. The infant's weight gain should be carefully monitored and supplementation considered as necessary.
2. Monitor the length of breastfeeds (e.g., limit to 1 hour) to ensure the infant is not becoming overtired from feeding.
3. Inform mothers that sucking efficiency frequently continues to improve over the first year, so that the breastfeeding experience may "normalize" and expressing, supplementation, diary keeping, and other interventions may no longer be necessary.
4. If breastfeeding does not continue to improve, assess the infant for other causes of breastfeeding difficulties (e.g., ankyloglossia).
5. Provide information about local support groups for breastfeeding and for specific diagnoses such as Trisomy 21. Because of the additional patience and time that are sometimes required to breastfeed these infants, support and encouragement are particularly important for mothers and families.
6. If maternal milk supply does not equal or exceed the infant's needs, or begins to slow despite optimal breastfeeding and/or expressing, the use of galactagogues to enhance maternal milk supply may be considered. See Academy of Breastfeeding Medicine Protocol #9 (Use of Galactagogues in Initiating or Augmenting Maternal Milk Supply).<sup>39</sup> (III) Supplementation with pasteurized donor milk is an option if supplementation becomes necessary and donor milk is available.<sup>26</sup>

#### 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 infants with hypotonia. It is also one of only a handful addressing breastfeeding and children with special needs. Although this population especially has need of evidence-based breastfeeding practices, there is little scientific evidence upon which to base recommendations. Little new research exists for this revision and we continue to extrapolate best practice from other vulnerable patient populations. Specific areas recommended for further research include the following:

1. Research into best practices for breastfeeding infants with special needs is scarce and needs to be

come a priority. These mothers and children stand to gain much from a successful breastfeeding experience and we require better information on how to support the family in that effort.

2. Methods of optimizing the hypotonic infant's suck and milk transfer require further study.
3. Use of pacifiers in premature infants as "practice" oral feeding during gavage feeds has assisted with the transition to breast in preterm infants, and merits evaluation in hypotonic infants when needed.<sup>40</sup>
4. Accurate means to evaluate normal growth in breastfed versus formula-fed hypotonic infants, especially those with Trisomy 21, once breastfeeding has been established, should be developed.
5. Evidence of the efficacy of different methods available to supplement hypotonic infants (cup, bottle, and spoon) to help determine best practice should be explored.
6. Information on how modifiable factors such as positioning, labor analgesia/anesthesia, skin-to-skin contact, and counseling in the perinatal period may compound or ameliorate the difficulties with breastfeeding in these infants should be available to assist in developing best practice standards.
7. Research into the risk of aspiration while breastfeeding compared with bottle feeding breastmilk (thickened or not) or formula in this population should be conducted, as this is a common concern for the hypotonic infant and may lead to premature and possibly preventable cessation of breastfeeding.

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ABM protocols expire 5 years from the date of publication. Content of this protocol is up-to-date at the time of publication. Evidence-based revisions are made within 5 years or sooner if there are significant changes in the evidence.

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