Nonoral Feeding for Children and Youth With Developmental or Acquired Disabilities

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Key Words
nonoral feeding, gastrostomy, fundoplication, shared decision-making, disabilities

Abstract
The decision to initiate enteral feedings is multifaceted, involving medical, financial, cultural, and emotional considerations. Children who have developmental or acquired disabilities are at risk for having primary and secondary conditions that affect growth and nutritional well-being. This clinical report provides (1) an overview of clinical issues in children who have developmental or acquired disabilities that may prompt a need to consider nonoral feedings, (2) a systematic way to support the child and family in clinical decisions related to initiating nonoral feeding, (3) information on surgical options that the family may need to consider in that decision-making process, and (4) pediatric guidance for ongoing care after initiation of nonoral feeding intervention, including care of the gastrostomy tube and skin site. Ongoing medical and psychosocial support is needed after initiation of nonoral feedings and is best provided through the collaborative efforts of the family and a team of professionals that may include the pediatrician, dietitian, social worker, and/or therapists. Pediatrics 2014;134:e1745–e1762

Introduction
The decision to initiate enteral feedings is multifaceted, involving medical, financial, cultural, and emotional considerations. In 1793, John Hunter wrote of a patient who had a neurologic impairment affecting swallowing: “It becomes our duty to adopt some artificial mode of conveying food into the stomach, by which the patient may be kept alive while the disease continues.” Today we speak of surgical options, medical options, and evidence-based outcomes; caregivers’ beliefs and roles; patient-appropriate individual intervention; family-centered care; and quality of life (QOL) considerations.

Faced with medical, social, and cultural considerations, the family often relies on the pediatrician for guidance in both the decision-making and the management of nonoral feedings. This article integrates cross-discipline information into a functional guide for the pediatrician. Specifically, this clinical report provides:

- an overview of clinical issues in children who have developmental or acquired disabilities that may prompt a need to consider nonoral feedings;
- a systematic way to support the child and family in clinical decisions related to initiating nonoral feeding;
information on surgical options that the family may need to consider in that decision-making process; and

pediatric guidance for ongoing care after initiation of nonoral feeding intervention.

BROAD CONSIDERATIONS IN THE NEED FOR NONORAL FEEDINGS

Children who have developmental disabilities or acquired disabilities are at risk for having primary and secondary conditions that affect growth and nutritional well-being. These conditions can manifest as inadequate intake of micronutrients, calories, and/or fluids. Prevalence rates vary greatly, even within diagnostic cohorts. Nonetheless, evidence from the past 2 decades supports the ability to improve nutritional outcomes among children who have neurologic disabilities (eg, cerebral palsy, Rett syndrome, trisomy 21, myelomeningocele).2–4

Deficiencies in micronutrients may develop in children who have underlying metabolic disorders who are treated with medically prescribed specialized diets, such as low-protein diets in patients who have urea cycle disorders. Some caregivers may also self-prescribe special diets to their children, in attempts to organically improve the underlying developmental disability. There is no substantial evidence supporting the addition of generic micronutrients as long as the child’s caloric needs are being met through a balanced diet. Restrictive diets may lead to significant nutritional deficiencies unless appropriately monitored.

Among youth who have suboptimal dietary intake, several deficiencies occur more commonly than others. For example, iron deficiency, a relatively high-risk condition for children who have feeding disorders, can affect well-being even when the iron deficiency has not yet created an actual anemia.5 It has been associated with sleep disorders in children and manifestations of inattention.6,7 Zinc is important in neurodevelopment; its deficiency is associated with a variety of symptoms, including loss of appetite and skin problems. For patients who have chronic nutritional stressors and comorbid developmental disabilities—particularly if surgery is being planned—the status of other vitamin and micronutrient stores may need consideration.8,9 For children who are fed prepared formulas (oral or nonoral) as the primary source of nutrition, micronutrients are provided in sufficient amounts only if the adequate amount of formula is actually being consumed and tolerated.10

Many youth who have developmental disabilities have comorbid conditions requiring medications. The potential for reciprocal interaction exists: the influence of medication on nutritional status, and the effect of nutritional status on bioavailability and metabolism of medications. Some medications have adverse effects, such as nausea, diminished appetite, or diarrhea. Antiepileptic drugs can be associated with secondary deficiencies of nutrients such as vitamin D and carnitine. Table 1 includes medication categories and their relationship to nutritional status. For some families, the ability to accurately administer medications orally can be problematic because of dysphagia, dystonia, other disorders of movement or coordination, or clinically significant reflux or emesis.

Among children who have neurodevelopmental disabilities, barriers to adequate oral intake can be related to underlying neurologic dysfunction. The enteric nervous system, developing primarily from the neural crest cells, is the so-called “brain of the gut.” Although it functions independently of the central nervous system (CNS), it also interacts with the CNS by prevertebral ganglia of the spinal cord and/or via the efferent action of the vagus nerve. Among children who have underlying differences in CNS development, associated dysfunction in gut motility or gastroesophageal reflux (GER) can contribute to the challenges of ensuring adequate nutritional intake and absorption. Sometimes these problems are progressive and degenerative; it is not uncommon for children who have disorders of energy metabolism (such as mitochondrial disorders) to experience worsening gut dysmotility over time.

Vomiting or retching is relatively common among children who have developmental disabilities. The underlying cause of these can inform decisions about approaches to nonoral feeding. Vomiting attributable to GER can be addressed through a combination of positioning, food or formula selection, medications, assurance that constipation has been alleviated, and/or surgery. Retching is the first stage of the emetic reflex and is not always related to GER. Poor modulation of gastric vagal afferents can act as a potent activator of the forceful emetic reflex. Recognition of this CNS process as the etiology of emesis is important, because this process may well continue even after a fundoplication procedure and can have a negative effect on the surgery’s long-term success.11–13 Dysmotility, mentioned previously, can also be a contributor to vomiting or retching.

Oropharyngeal incoordination, resultant poor bolus formation, and/or inadequately controlled bolus propulsion can result in subsequent airway penetration or outright aspiration. If sustained, chronic pulmonary dysfunction and/or reactive airway disease can result. These problems, in isolation or in addition to GER or gut dysmotility, may diminish the child’s desire to eat orally.14

Frank aspiration identified in modified barium swallow studies invites the discussion of moving to a nonoral feeding route. However, these studies are rarely so “black and white.” Penetrations of
some textures may merely require alteration of oral feeding techniques. Techniques of bolus size selection and pacing of bites, for example, may allow a somewhat tedious but acceptable method for continued oral feedings. Thus, these studies may inform decisions, but should not, in isolation, mandate surgical intervention.

Suboptimal fluid intake leads to chronic intermittent constipation. This, in turn, can result in diminished appetite. The circular pattern of a feeding disorder, leading to diminished safe fluid intake, resulting in constipation, contributing to further feeding disincentives and even emesis, is too common among children who have neurodevelopmental disabilities.

SPECIFIC CONSIDERATIONS: CHILDREN WHO HAVE A NEED FOR NONORAL FEEDINGS

Detailed description of the vast array of neurodevelopmental or acquired disabilities and their unique nutritional challenges is beyond the scope of this report. In particular, 2 important complex cohorts of children are not included: (1) very preterm or sick neonates being managed in a neonatal ICU, and (2) children receiving prolonged total parenteral nutrition. Presented below are examples of common conditions associated with nutritional/feeding challenges among children who have special health care needs. Hopefully, these can guide approaches to care for the broader array of children who have special needs seen in pediatric clinical settings.

Children Who Have Cerebral Palsy

Cerebral palsy refers to a group of static brain insults affecting the development of movement and posture, often with differences in tone (diminished, increased, or mixed). The functional implications of insults occurring in early development can extend beyond motor impairments to impairments of visual-motor skills, communication, cognition, and behavior. Similarly, neuromuscular and enteric nervous system dysfunction can manifest as ongoing or worsening issues. Comorbid conditions, such as seizure disorders, hearing impairments, abnormal muscle tone, or postural instability, can be present. Any of these factors (or multiple combinations) can affect eating and swallowing skills, leading to nutritional compromise.

Feeding problems for children who have cerebral palsy may manifest as oral fluid/food spillage while feeding, increased length of meals (often confused as “behavioral”), coughing/gagging with feeding, recurrent lower respiratory infections, GER, and/or nasal reflux from the posterior pharynx. These or other “red flags” suggestive of dysphagia should be considered when the child fails to grow or maintain appropriate health.

For decades, identifying the best method to evaluate and monitor growth and nutrition in children who have cerebral palsy has challenged pediatricians. Weight, weight-for-height, segmental measures, skinfold measures, and other techniques each have some value, but none is easily and consistently applied.

### TABLE 1 Potential Clinical Problems in Selected Medication Use and Nutritional Status

<table>
<thead>
<tr>
<th>Category</th>
<th>Medication (Examples)</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticonvulsants</td>
<td>Valproate</td>
<td>Potential for carnitine, folate, copper, selenium, and/or zinc deficiency</td>
</tr>
<tr>
<td></td>
<td>Phenytoin</td>
<td>Potential for folic acid, calcium, vitamin B6, vitamin D, and/or vitamin K deficiency</td>
</tr>
<tr>
<td></td>
<td>Phenobarbital</td>
<td>Potential for folic acid, calcium, biotin, vitamin D, and/or vitamin K deficiency</td>
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<tr>
<td></td>
<td>Carbamazepines</td>
<td>Potential for biotin, folic acid, and/or vitamin D deficiency</td>
</tr>
<tr>
<td></td>
<td>Lamotrigine</td>
<td>Occasional nausea and/or vomiting</td>
</tr>
<tr>
<td></td>
<td>Levetiracetam</td>
<td>Potential for biotin, folic acid, and vitamins B6 and/or B12 deficiency</td>
</tr>
<tr>
<td></td>
<td>Topiramate</td>
<td>Renal tubular acidosis and pancreatitis, renal/bladder stones</td>
</tr>
<tr>
<td>Stimulants</td>
<td>Methylphenidate and associated stimulants used in attention-deficit/hyperactivity disorder</td>
<td>Appetite suppression, slow height growth, potential for weight loss</td>
</tr>
<tr>
<td>Muscle relaxants</td>
<td>Diazepam and others in this class</td>
<td>Highly protein bound, with malnourishment and loss of serum protein may be enhancement of drug effect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Take into consideration re: pain management, respiratory depression</td>
</tr>
<tr>
<td>Corticosteroids</td>
<td>Dexamethasone</td>
<td>Increased appetite or diminished appetite; impact on taste, diminished calcium and phosphorous absorption; increased risk for gastritis</td>
</tr>
<tr>
<td>Antibiotics</td>
<td></td>
<td>Potential for diarrhea related to gut flora change, probiotic therapy shown to minimize adverse effects</td>
</tr>
<tr>
<td>Antidepressants</td>
<td></td>
<td>Reports indicate that among individuals who have major depressive disorder, there may be deficiencies in folate, vitamin B12, iron, zinc</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>Oxybutynin</td>
<td>Constipation, dry mouth</td>
</tr>
</tbody>
</table>
with assurance of accuracy across the population of children who have cerebral palsy.\textsuperscript{21,22}

In the pediatric medical home, serial measures of the child’s weight remain the most common practice; this offers a useful way to track trends in growth and nutrition longitudinally. Obtaining consistent measures in a clinic setting can be challenging but can be enhanced by use of a consistent scale (balanced to 0 at each visit) and by weighing the child consistently in light clothing, with a dry diaper, and without shoes, orthotic bracing, wheelchairs, or other confounders. Weights should be plotted on standard growth charts at each visit.\textsuperscript{23,24}

Consultation with a pediatric dietitian can be useful when there are declines in trends of weight, struggles with feeding/drinking patterns, GER, constipation, or compromised bone health. A detailed analysis of protein, fluid, caloric, or fiber intake; mealtime patterns; socioeconomic factors; and behavioral factors can facilitate approaches to optimal intake and growth. The overall energy expenditure of the child, including changing manifestations of spasticity or dystonia, deserves consideration when changing trends in weight are noted.\textsuperscript{25} After the aforementioned factors have been addressed in an effort to support successful oral feeding, if the child remains unable to safely and effectively meet his or her nutritional requirements orally, options for adjunctive nonoral feedings should be considered.

**Children Who Have Myelomeningocele**

A common feature among children who have myelomeningocele is the presence of a Chiari II malformation, which can be associated with central apnea and/or dysphagia. In infants, the “suck, swallow, breathe” rhythm can be disrupted. Excessive gag reflex can be confused with GER. Children who have vocal cord dysfunction related to the Chiari II malformation may require tracheotomy; not uncommonly, nonoral feeding via gastrostomy tube is recommended for pulmonary safety.

Development of the enteric nervous system takes place as neural crest-derived cells migrate and differentiate.\textsuperscript{26} Dysmotility in children who have spina bifida, related to alterations in the enteric nervous system and altered parasympathetic innervations, can manifest from the esophagus downward throughout the intestinal tract. Modified barium swallow studies performed carefully to replicate actual feeding circumstances can be greatly helpful in symptomatic children. If alteration of textures and changes in feeding techniques fail to support adequate nutrition and/or safe oral feedings, options including nonoral feedings must be discussed. As children grow into early elementary school age, the anatomy of the head, oropharynx, and neck shift in relative proportions. A repeat modified barium study may be warranted to define new parameters of safe feeding.

Among children who have thoracolumbar-level myelomeningocele who demonstrate severe kyphoscoliosis, peculiar chest/abdomen anatomy, or both, feeding problems can occur related to posture, positioning, underlying internal anatomy, and GER. These, in concert with dysphagia related to the Chiari II malformation, create complex feeding challenges.

Adequate nutrition is critical to maintenance of skin integrity. Too often, the combination of insensate skin, moist skin, and exposure to local tissue injury results in significant wounds among children who have myelomeningocele. Successful management of serious wounds demands higher intake of protein, calories, and micronutrients.\textsuperscript{27} Children who are marginally able to meet their fluid and nutritional needs orally may need adjunctive feedings for relatively short duration (8 weeks or less) to promote wound healing; others may require nonoral feeds for longer periods.

**Children Who Have Cleft Conditions and/or Micrognathia**

Micrognathia (mandibular hypoplasia) has its origin in the first trimester of intrauterine development. The abnormally high position of the tongue can result in a cleft of the soft palate. A severe form of this process results in the Robin sequence. The recessed jaw and tongue are often associated with low tone and weakness of facial musculature, increasing the risks for airway obstruction and aspiration of oral feedings.\textsuperscript{20} For infants affected by these conditions, nasogastric tube feeding or gastrostomy tube feeding may be required from birth for months at a minimum.\textsuperscript{28} Reid and colleagues provide an excellent review of feeding issues relative to cleft lip, cleft palate, Pierre-Robin sequence, and other cleft conditions. Their longitudinal studies spotlight the conditions for which adjunctive nonoral feeding measures might be indicated.\textsuperscript{29}

**Children Who Have Neurodevelopmental Disabilities**

GER is a common finding among children who have neurodevelopmental disabilities.\textsuperscript{30} The reflux can be related to a spectrum of underlying and sometimes uncommon conditions, including anatomic conditions, such as hiatal hernias or structural anomalies. *Helicobacter pylori* gastritis as a cause remains a point of debate.\textsuperscript{31,32} Celiac disease can be a comorbid condition in various genetic syndromes.\textsuperscript{33,34} Behavioral characteristics, related to underlying pain or temperament differences, can be confused with GER. Eosinophilic esophagitis should be considered in the differential diagnosis, especially in...
children not responding to appropriate reflux management.\textsuperscript{35}

It is important to also consider a primary underlying central nervous system injury in the differential. For example, a group of infants who had either perinatal injury or dysphagia without specific etiology were found to have high-intensity lesions in the lower pons and medulla and pontomedullary atrophy on MRI studies. This suggests that a vagovagal reflex, mediated by brainstem function, might contribute to the disturbed motility of the upper digestive tract in some children.\textsuperscript{15}

Children who have genetic syndromes and other developmental disabilities often require elective surgeries for a variety of reasons, such as scoliosis, contractures, and hip dysplasia. Because of the hardware inserted, casts applied, or the required postsurgical positioning, their previous unique posture for feeding may be compromised. If this “natural posturing” previously served as compensation for occasional aspiration or as assistance in moving and swallowing a bolus of food or fluid, then the potential for postoperative pulmonary events can be increased. Preoperative planning by the surgeon, the pediatrician, the pediatric hospitalist, the family, speech or occupational therapists, and the dietitian allows for presurgical intervention to minimize such risks. Table 2 outlines some presurgical considerations.\textsuperscript{36} On the basis of a holistic assessment, consideration of nonoral feeding for a period before surgery (for optimal nutritional stores and pulmonary status) and for a period postsurgery (for wound healing and airway safety) may be necessary.

**Children in Palliative Care**

Elements of ethical decision-making are recurring considerations in the daily and year-to-year care of children who have developmental or acquired disabilities. Often, decisions are made without deliberate attention to conversations about prognostic or ethical implications. The Association for Children's Palliative Care published a *Guide to the Development of Palliative Care Services*, which includes information about children who have developmental disabilities.\textsuperscript{37} Some children receiving palliative care coordination may be in an imminent terminal-care stage; for others, the trajectory of deterioration may be months or longer. Because such prognostication can be difficult, special consideration and flexible planning for nutritional support is required. In some circumstances, families and members of their support system may decide against further nonoral nutrition/hydration interventions.\textsuperscript{37} Otherwise, nutritional support care plans should be devised (1) after identification of likelihood of risk for malnutrition (energy needs, nutrient needs, effects of medications, effects of underlying condition), (2) in concert with family, physicians, palliative care team, pediatric dietitians, and the speech pathologist focusing on oral-motor skills, (3) whenever safe and possible, to allow continued oral nutrition (with preferences of the child considered), and (4) to maintain energy, minimize pain or irritability, and focus on overall (not just health-related) QOL goals. These care plans may vary over time because of activity, mobility, tone issues, fever fluctuations, skin integrity, or acute illnesses.

The terminal nature of conditions warranting palliative care intervention places a spotlight on many decisions relative to care and support. Decisions related to nonoral feedings—adjunctively or solely—require sensitive awareness of individual needs. To greater or lesser degrees, similar shared decision-making is needed for any child being considered for nonoral feedings.

**SHARED DECISION-MAKING: A MULTIFACTORIAL PROCESS**

Ultimately the concerns outlined previously are helpful signposts, but no single clinical finding in isolation is an absolute indication to avoid all oral intake and move solely to nonoral feedings indefinitely. Rather, the multiple components serve as discussion

**TABLE 2 Considerations Before Surgical Procedures: Nutrition, Airway Safety, and Surgery: Considerations for Nonoral Feeding Intervention**

<table>
<thead>
<tr>
<th>Consideration</th>
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<tbody>
<tr>
<td>Developmental disability with known dysphagia, airway concerns</td>
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<tr>
<td>Significantly underweight/failure to thrive</td>
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<tr>
<td>Pulmonary function and reactive airway disease: status and optimal management</td>
</tr>
<tr>
<td>Suboptimal nutrient status (calories/vitamins/micronutrients/protein/iron/other)</td>
</tr>
<tr>
<td>Medication–nutrient interaction</td>
</tr>
<tr>
<td>Cultural requirements for special or specific diets</td>
</tr>
<tr>
<td>Financial/insurance issues related to pre- or postoperative nutrition support</td>
</tr>
<tr>
<td>Formulas</td>
</tr>
<tr>
<td>Equipment</td>
</tr>
<tr>
<td>Nursing or personal care assistance</td>
</tr>
<tr>
<td>Postoperative supplements likely to be needed</td>
</tr>
<tr>
<td>Potential need for total parenteral nutrition</td>
</tr>
<tr>
<td>Peripheral venous access versus central</td>
</tr>
<tr>
<td>Energy needs</td>
</tr>
<tr>
<td>Baseline</td>
</tr>
<tr>
<td>Anticipated NPO status for planned procedure</td>
</tr>
<tr>
<td>Wound-healing support</td>
</tr>
<tr>
<td>Likelihood of repeat operating room procedures requiring NPO status</td>
</tr>
<tr>
<td>Oromotor feeding</td>
</tr>
<tr>
<td>Iatrogenic factors likely to impact feeding abilities</td>
</tr>
<tr>
<td>Postoperative pain management plan and nutritional considerations</td>
</tr>
<tr>
<td>NPO, no oral intake.</td>
</tr>
</tbody>
</table>
points for collaboration among the patient, the family, and the health care professionals.

Considering both the clinical status and the social contexts of the child, questions to be considered include:
- Do they support adequate caloric, nutrient, and fluid intake?
- Do they support optimal health-related quality of life (HRQOL)?
- Do they support optimal QOL?
- Are the present conditions optimal? Safe? Psychosocially and clinically sustainable?
- Do they allow a combination of oral and nonoral intake?
- Is the present situation temporary, or is it likely to be ongoing or progressive?
- Are potential changes in feeding methods and schedules realistic for the family?

An informed and sensitive approach is in order. This is best accomplished using a cross-discipline approach. After discussion with the patient and the family, these decisions can be direct and straightforward, exceedingly difficult, or somewhere along that spectrum. Although families and professionals each use the term “quality of life,” this can be projected and/or perceived variably. Neither clinicians nor researchers have yet to agree on a universal definition of either QOL or the HRQOL categories (suggested even in the article’s title, “Eating and Feeding are Not the Same”). The complexities and contradictions in “coming to consensus” on this topic were nicely outlined with several concerns generated from families:
- Is the enteral feeding a confirmation of the permanence of the child’s disability?
- Will it increase discrimination and be viewed as additional stigma?
- Will it produce a loss of the nurturing, parental experience for the caregiver?
- Will it prevent “pleasure of eating” for the child?
- Will it prevent mealtime social associations?

Mahant et al conducted a qualitative systematic review of publications focused on the experiences of parents who had actively participated in the decision-making before initiation of nonoral feeding. The authors identified 3 major themes related to decision-making:
- Context: characteristics unique to the family, child, and the circumstances bearing on each
- Values: attitudes, beliefs, and belief systems affecting decisions regarding nonoral feedings for nutritional support
- Process: the perceived manner of decision-making in concert with health teams

Figure 1 offers a schematic of example factors contributing to decisional conflict or decisional resolution based on a modification of Mahant’s work. The outline supports the concept of shared decision-making to minimize conflict and enhance decisional resolution. For the pediatrician involved in this process, Shakespeare’s words are a useful reminder: “The web of our life is of a mingled yarn, good and ill together.” How the terms “good” and “ill,” “quality of life,” “medically necessary,” “comfort,” and others are defined is unique to the family, the child, and the clinical situation. Unminding the yarn requires time, sensitivity to the situation, and a knowledge base to provide information, support, and collaboration.

Beyond the emotional, social, cultural, or financial aspects of nonoral feedings, other clinical considerations include:
- Growth differences: growth failure, diminished growth trajectories
- Malnourishment
- Dysphagia and associated respiratory complications
- Skeletal problems or other comorbid conditions with links to nutritional concerns
- Neurologic conditions directly affecting gut motility and fecal evacuation
- Comfort, sleep, and behavioral issues manifesting in a poorly nourished child

Medical conditions resulting from or contributing to suboptimal growth and nutritional health should be assessed before recommending nonoral feedings. Table 3 lists laboratory and/or clinical evaluations that might be useful. Once consensus is reached to go forward with adjunctive feedings for nutritional support, more options await the family and support team. Figure 2 offers a decision-tree approach to the information that follows.

When oral feeding is deemed insufficient for adequate nutrition, an early consideration is: “How long is the nonoral feeding regimen likely to be needed?” If the estimate is a relatively short period (<8 weeks), use of
a nasogastric (NG) tube feeding regimen might be considered. If there is clinically significant preexisting GER, the alternative use of a nasojejunal (NJ) feeding tube may be advantageous. On the basis of the child’s primary and comorbid conditions, these tube feedings may be variably tolerated. Thus, families will need education on reinsertion of NG tubes; NJ replacement typically requires fluoroscopic guidance. The goal is resumption of oral feeding once the acute situation has resolved.

If adjunctive or total nonoral feedings are likely to be longer in duration, consideration of a gastrostomy button (or tube) should be considered. This is particularly appropriate for the child who is engaged in a “typical” environmental schedule (eg, school, community, sports). For children who have ongoing need for nonoral feedings, the gastrostomy tube is better tolerated physically, socially, and functionally than NG or NJ tubes. Several types of approaches and equipment are available as options: (1) a percutaneous and endoscopic procedure for gastrostomy button insertion, (2) a surgically placed button (or tube) into the stomach, or (3) gastrojejunal tube insertion.

Advantages and constraints of the various methods of nutritional delivery should be a part of the shared decision-making process. For example, the family can “bolus” feedings (deliver an adequate-volume “meal” in a relatively short timeframe) via the NG tube or the gastrostomy button when GER or excessively delayed stomach emptying are not serious concerns. Alternatively, extended-time feedings are necessary when jejunal feedings are required.

Before placement of a gastric button in a child who has neurodevelopmental disorders, there should be
consideration of signs or symptoms of delayed gastric emptying. If emptying is somewhat slow, this can be improved through altering formula selection, volumes per feeding, schedule of feedings, or rate of feedings and with medications such as erythromycin or metoclopramide. If the emptying time is significantly delayed and these considerations are not accounted for, the child remains at risk for emesis, discomfort, and potential aspiration.44

Excluding decisions for nonoral feedings that are precipitated by acute severe medical/surgical/traumatic emergencies, the ultimate decision to move forward with nonoral feedings can best be supported if the family has had a preceding and continuing relationship with a pediatric dietitian. Nutritional guidance and information sharing is central to the care of the child who has developmental or acquired disabilities; thus, the dietitian should be included in the core decision-making team. Micronutrient composition of formulas and the caloric requirements of the individual child vary; they require close monitoring and direction.45,46 Nutritional assessments periodically allow for earlier identification of the at-risk child. Having a preexisting understanding of the family’s concerns and values provides greater credibility when more difficult conversations and decision-making are required.47 A strong alliance between the pediatrician, the speech therapist, and pediatric dietitian—whether within the pediatric office or at a location for ready access—will facilitate a comprehensive and individualized plan of care.48

TABLE 3 Clinical Laboratory Tests and Other Clinical Studies That May be Useful Before Nonoral Feedinga

<table>
<thead>
<tr>
<th>Clinical Investigation</th>
<th>Specific Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Serum</td>
<td>Iron panel and serum ferritin</td>
</tr>
<tr>
<td></td>
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<td>Urine analysis</td>
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</tr>
<tr>
<td></td>
<td>If clinically indicated, nuclear medicine gastric emptying study</td>
</tr>
<tr>
<td>Biopsy/scope</td>
<td>Eosinophilic esophagitis</td>
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<tr>
<td></td>
<td>Celiac disease, gastritis</td>
</tr>
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</table>

a Investigations listed are meant as a guide for thoughtful consideration, not a standard of practice.

FIGURE 2
Decisions in adjunctive feedings of the child/adolescent with developmental disabilities.

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a Investigations listed are meant as a guide for thoughtful consideration, not a standard of practice.

FIGURE 2
Decisions in adjunctive feedings of the child/adolescent with developmental disabilities.

FIGURE 2
Decisions in adjunctive feedings of the child/adolescent with developmental disabilities.
referral—best serves the families of children who have disabilities.

OUTCOMES STUDIES THAT INFORM DECISION-MAKERS

As families consider (1) surgical placement of a gastrostomy button as an adjunct to or for replacement of oral feedings, and (2) the advisability of a gastric fundoplication for comorbid GER, the need for best evidence of optimal outcomes arises. Studies of children and families have been published describing outcomes of gastrostomy tube placement and feeding. Although limited in scope and number, the outcomes provide the pediatrician and the families with some data for decision-making (Table 4). Extant literature suggests that if the decision points outlined previously are addressed and the medical needs are identified, the pediatrician can assure parents and children that the nonoral feeding option can be positive. This can be stated in regard to both physical and QOL considerations. Variance in adverse events point to the “operator-dependent” nature of the surgical procedures, to pre-existing comorbidities, and to supportive aftercare.

The psychosocial and emotional considerations in qualitative outcome studies emphasize the value of physician-to-parent and parent-to-parent support in decision-making regarding nonoral feeding. Conversations about what constitutes “normal” can help to alleviate an overwhelming sense of disappointment or guilt in going forward. “Normal nutrition” involves adequate fluid intake, adequate caloric and nutrient intake, achieving a sense of satiety, achieving typical growth patterns, safety in delivery of food (eg, avoidance of aspiration), and good health. Often these components are compromised in oral feeding of children who have disabilities but are improved with adjunctive and/or replacement nonoral feedings.

Support for the child and family should begin well before decision-making and placement of the gastrostomy tube. Protocols for educating and instructing families about the gastrostomy tube can inform the clinical decision process. Such protocols can include hands-on feeling of the devices, doll models for adults and children alike to better understand anatomy, drawings, and verbal reinforcement. This information is valuable early in decision-making, but reinforcement is needed in the months and years thereafter as the child grows and new situations require updating of feeding regimens.

Fundoplication Surgery

The need for antireflux intervention is a common topic as families consider gastrostomy tube placement. When pharmacologic and/or dietary interventions have been exhausted, a common surgical option is the Nissen fundoplication (or a modification). The goals of fundoplication include (1) restore the intra-abdominal esophagus, (2) restore the angle of His, (3) reconstruct the diaphragmatic hiatus (when necessary), and (4) reinforce the lower esophageal sphincter and increase basal lower esophageal sphincter pressure.48 The value of fundoplication surgery with or without gastrostomy tube placement has, for decades, been a focus of debate and contradiction. To some degree, it remains so even now. When GER is highly suspected clinically before gastrostomy tube placement, evaluation by nuclear medicine, direct endoscopic visualization/biopsy, classic pH, or multichannel intraluminal impedance-pH studies are options for assessment.49 Despite the advancement of technical methods of measuring esophageal parameters, ongoing lack of clarity remains as to the clinical relevance of the measurements and their predictive value after surgery.44,50-52

Again, evidence-based outcome studies—limited as they are—provide an element of understanding when advising families. Unlike the studies on gastrostomy tube placement outcome, the data from studies related to fundoplication surgery fail to suggest which patients might be best suited for the procedure. For example, a study of reflux using multichannel intraluminal impedance-pH studies provides insight into the technical challenges in administering the examination, although the patients described excluded children who have overt neurologic disorders, metabolic disorders, or respiratory and/or gastrointestinal malformations.53 In response to earlier suggestions for “the need for a ‘protective’ antireflux operation in children referred for feeding gastrostomy,”54 Puntis et al provided data “in the child with neurological disabilities without symptoms indicating severe gastroesophageal reflux” and their conclusions that “fundoplication is unlikely to be necessary as a consequence of percutaneous endoscopic gastrostomy” and that the number of antireflux surgical procedures should be reduced.55 Similarly, the outcome reports of variations in fundoplication techniques (eg, open, laparoscopic) offer differences in respective advantages and disadvantages.56,57

A number of complications and adverse effects have been described and attributed to fundoplication surgery: alterations in gastric tone (perhaps related to injury of the vagal nerve at operation); accelerated gastric emptying (“dumping syndrome”); delayed gastric emptying after surgery related to vagal nerve injury; and retching (potentially related to visceral afferent sensitivity and vagal nerve injury). The gas bloating syndrome (inability to belch and vomit, abdominal pain after eating, and/or dysphagia) can result from 1 or more of these complications.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Subject</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Craig et al, 2006&lt;sup&gt;85&lt;/sup&gt;</td>
<td>Medical, surgical, and health outcomes of gastrostomy feeding</td>
<td>Prospective study; before and after gastrostomy; 76 children with neurodevelopmental disabilities and families. Two thirds of those with severe weight issues before achieved mean weight-for-age ((P = .001)). Other health gains included reduction in drooling, decreased secretions, less vomiting, improved constipation. Thirteen children after surgery had a significant complication (eg, internal fistula, adhesions, bleeding).</td>
</tr>
<tr>
<td>Enrione et al, 2005&lt;sup&gt;86&lt;/sup&gt;</td>
<td>Medical and psychological experiences of family caregivers with children fed nonorally</td>
<td>Qualitative study addressing the caregivers of children with gastrostomy tube feedings and whether they had problems and/or concerns themselves. Questionnaires sent to 150 families (37 participated). Major psychosocial issues included: “I feel sad because my child is deprived of many social activities that involve eating”; “I feel depressed about not being able to feed my child by mouth,” “In my absence, I have trouble finding (someone to) feed my child.” Over the course of the year after surgery, the medical concerns became less and the ranking of psychosocial issues increased.</td>
</tr>
<tr>
<td>Mahant et al, 2009&lt;sup&gt;87&lt;/sup&gt;</td>
<td>Tube feeding and quality of life in children who have severe neurologic impairment</td>
<td>In general, caregivers reported a positive effect on the child’s health, particularly with regard to feeding, administration of medications, and weight gain. Based on use of nonvalidated questionnaire that used visual analog scale. Procedure deemed “safe” and with “few major complications” by parent reports.</td>
</tr>
<tr>
<td>Martinez-Costa et al, 2011&lt;sup&gt;88&lt;/sup&gt;</td>
<td>Early decision of gastrostomy in children who have severe developmental disability</td>
<td>Structured telephone script allowed input from parents of 26 children with severe disabilities. Caregivers “showed high satisfaction (91%)” and 87% noted they would have decided earlier to go forward with gastrostomy “had they anticipated the outcome.” Patient management and family dynamics (including the child) were noted to have “improved considerably.”</td>
</tr>
<tr>
<td>Samson-Fang et al, 2003&lt;sup&gt;89&lt;/sup&gt;</td>
<td>Effects of gastrostomy in children who have cerebral palsy using the AACPDM method for evidence reports</td>
<td>This important review considered previous outcome studies from 1956 through 2002, offering historical perspective in addition to detailed descriptions of studies and outcomes. Generally, the report cited less than robust levels of evidence and the need for further well-designed studies. There was a general consensus (low levels of evidence) of gastrostomy placement being “helpful.”</td>
</tr>
<tr>
<td>Sleigh and Brocklehurst, 2004&lt;sup&gt;90&lt;/sup&gt;</td>
<td>Effects of gastrostomy feeding in cerebral palsy: another systematic review</td>
<td>This evidence-based review from the United Kingdom resulted in findings similar to those of Samson-Fang in 2003 and encouraged further studies with higher levels of evidence.</td>
</tr>
<tr>
<td>Sullivan et al, 2004&lt;sup&gt;91&lt;/sup&gt;</td>
<td>Impact of gastrostomy feeding on the quality of life of caregivers to children who have cerebral palsy</td>
<td>Although the purpose of gastrostomy placement is solely for the care and benefit of the child, the parents continue to act as the “partners in feeding.” Caregivers of 57 children with cerebral palsy reported significant reduction in feeding times, increased ease of drug delivery, and reduced concern about their child’s nutritional status. In concert with these findings, the caregivers reported (12 mo after gastrostomy placement), that they, themselves, had significant improvement in social functioning, mental health, energy/vitality, and general health perception.</td>
</tr>
<tr>
<td>Wilken, 2012&lt;sup&gt;92&lt;/sup&gt;</td>
<td>A qualitative meta-analysis of maternal emotional state after initiating tube feeding in their child</td>
<td>A review of 7 qualitative studies (1997–2007). Both oral and tube feeding have multiple meanings for parents and “signify more than obtaining an adequate nutritional intake.” Decisions about gastrostomy tube placement are complex and often difficult. A significant percentage of mothers noted lack of support during the decision-making process. After the tube insertion, there was description of both relief and disappointment (in “giving in” to the nonoral feeding).</td>
</tr>
</tbody>
</table>
The onset of postsurgical dumping syndrome (which can be observed irrespective of presurgical gastric emptying time studies) has been reported. Treatment of this condition can be approached by use of thickeners, selective formulas, nutritional supplements to formula being used, and pureed feedings in addition to or rather than formula only. If dumping syndrome is suspected and/or sustained, collaborative consultation with a gastroenterologist for formal diagnosis and collaborative treatment plans should be considered. Thus, on the broad question of “Is my child a good candidate for fundoplication?” recent clinical studies and reviews leave physicians and families very much where they have been for decades: fundoplication for the control of GER in children needs further evaluation. Given the lack of strong data from outcome studies with high levels of evidence, the decision for or against fundoplication at the time of gastrostomy tube placement remains a highly individual judgment. The severity of the reflux and its effects on the child, the response to previous vigorous medical treatment of GER, the outcome experiences of and opinion of the pediatric surgeon (relative to fundoplication procedures), and comorbid medical/developmental conditions (ie, tracheotomy) are examples of components in the decision-making process. Qualitative studies and those focusing on HRQOL generally reflect a positive experience for the child and family after fundoplication.

**POSTOPERATIVE SUPPORT AND COLLABORATIVE CARE**

Although the choice for surgery can be considered a “landmark” decision, ongoing medical and psychosocial support is needed for an extended period after the procedure. This follow-up is best provided in the context of a collaborative commitment involving family, pediatrician, and colleagues, such as the dietitian, speech pathologist/occupational therapist, and social worker. Collaborative care is outlined in 3 categories: (1) the roles of professionals and caregivers, (2) care of the gastrostomy tube and skin site, and (3) coordination of oral and nonoral feeding goals.

**Roles of Pediatrician, Pediatric Dietitian, and Caregivers**

For families, the process of surgery, equipment procurement, formula prescriptions and delivery, and ongoing care can become fragmented and problematic. Gordon et al described the value (emotional, financial, and medical) of a closely interconnected partnership between the tertiary care providers (such as developmental pediatric dysphagia teams) and the primary care physician for medically complex and fragile children who have special health care needs. Particularly valued by families was having a single “point professional” (eg, nurse, coordinator) at the primary care office and at the tertiary care center as their portals of entry; likewise, having those 2 resources in communication was deemed important.

On some periodic basis, specific inquiry of the family as to how the feedings are going provides an opportunity to acknowledge the long-term decision and to gather answers to specific questions/concerns about the process: effect on siblings; time and scheduling of feedings if different from other family members; need for advocacy relative to agencies, schools, child care facilities, or other; description of typical day and night schedule; most difficult aspect of the nonoral feeding at particular times (if any); level of perceived well-being by the primary caregiver(s); and any effects (positive or negative) on the child’s social activity and participation.

Medical considerations for the long-term include monitoring for multiple associated conditions in similar ways to those focused on before surgery:

- Undernutrition, overweight, micronutrient deficiencies, food allergy-associated eosinophilic esophagitis
- Dental (gum and teeth) health status
- Medication changes from other subspecialists (eg, seizure medications)
- Pulmonary status and sleep status and their potential relationships to feedings
- Changing body structure (eg, scoliosis, osteopenia)
- Changing body function (eg, strength, tone, gut motility, oral motor dysfunction)
- Skin health, particularly around the gastrostomy tube site

The Pacific West Maternal & Child Health Distance Learning Network – CSHCN Nutrition (http://depts.washington.edu/chdd/ucedd/ctu_5/pacwestcschn_5.html) offers a series of modules on nutrition for children who have special needs that are clinically relevant and supportive to the primary pediatrician. The Academy of Nutrition and Dietetics has created “Standards of Practice and Standards of Professional Performance for Register Dietitians (Competent, Proficient, and Expert) in Intellectual and Developmental Disabilities.” Dietitians who have met criteria for “proficient” or “expert” in this field can be a remarkable resource to families and physicians alike when addressing ongoing clinical issues of nonoral feedings: construction of long-term nutrition plan; integration of feeding into home, skilled nursing, or school settings; updating feeding needs; problem solving (mealtime supports, technical feeding issues, communication skills of the child, changing levels of interdependence); advocacy with supporting agencies; and monitoring of nutritional status over time. See example forms
in Figs 3 and 4 for use in supporting families.

**Care of Gastrostomy/Gastrojejunal Tube**

Even if the care of the gastrostomy tube and associated conditions are managed mostly through the tertiary care center, the family is well served by the primary medical home that is familiar with care and maintenance of the gastrostomy button. For the pediatrician, helpful resources include:

- [http://www.vygon.co.uk/pdf/upload/Enteral_Feedingfull.pdf](http://www.vygon.co.uk/pdf/upload/Enteral_Feedingfull.pdf)
- [http://www.slideshare.net/jessicalynn-smith/finalpresentation-13485393](http://www.slideshare.net/jessicalynn-smith/finalpresentation-13485393)

These tutorials provide information on types of feeding tubes, stoma site care, tube maintenance, tube removal and replacement, and tips for problem solving. Beginning in 2014, a global initiative began to institute a unified set of industry standards for safer connectors that ensure compatibility and reduce the likelihood of tubing misconnections in enteral feeding systems.

Differences remain among pediatricians and surgeons as to their personal preferences for gastrostomy button replacement: some set a particular calendar schedule; others suggest a change only when the current button is failing. Regardless, families should have available at all times either a spare button or Foley catheter (same diameter size as button) for unexpected loss of the gastrostomy button. If an emergency department or medical office is not immediately available, the family should know how to replace 1 of these until they can be seen by a medical professional.

Incorrect medication delivery through the tube can result in clogged tubes, decreased drug delivery, and/or drug-formula incompatibilities (particularly common: phenytoin, carbamazepine, fluoroquinolones, and proton pump inhibitors). Most medications should not be added into the enteral formula bag. Medications need to have the tubing line flushed with warm water before and after dosing. If in question, consultation with a pharmacist will inform as to which medications can be crushed and used in which vehicle liquids.74,75

Many times, the “venting tube” (or “burping tube”) that accompanies the replacement gastrostomy button kit is a highly valuable tool. For children who air-swallow and whose gastric air collection is interfering with feeding (bloating, distention, discomfort), use of the venting tube before and after feeding can ease these symptoms considerably.

Generally, the stoma site should be washed and cleansed as is the remainder of the chest and abdomen: washed with a pH-balanced bath soap, then left uncovered for access to open air. For the occasions when the site allows leakage, an absorptive wound care foam dressing will “wick” the moisture away from the skin more efficiently than cotton gauze pads.

The development of overgranulation tissue at the stoma site is not uncommon. The specific etiology of its development is not known, but several contributing factors have been suggested: reaction to a foreign body, undue pressure, repeated “trauma” or friction to the area, or excessive moisture to the area. An excellent literature review and subsequent care pathway to evaluate and manage overgranulation was provided by Warriner and Spruce76; suggestions included:

- Silver nitrate applications have historically been used, but care must be taken to avoid damage to the tube, damage and pain to surrounding skin, and potential for further tissue damage or secondary infection at the site of the granulation tissue.
- Topical use of low-dose steroids has been evaluated; a specific tape (Haelen tape) impregnated with an appropriate steroidal preparation has been shown to be effective.77,78
- If persistent, therapies used in wound care centers can be applied.
- If aggressive topical therapies are not eliminating the tissue and it is considered to be a problem (eg, bleeding, drainage onto clothing, odor, aesthetic), removal and replacement of the button/tube can sometimes help.

In the child whose dysmotility or reflux symptoms are being managed by use of a gastrojejunal tube rather than by gastrostomy and fundoplication procedure, its replacement generally requires fluoroscopy with the assistance of interventional radiologists. Migration of the gastrojejunal tube’s tip from the intestine back into the stomach can result in regurgitation and aspiration. If suspected, feedings should be halted; consultation with the physician is warranted. Radiographic evaluation and tube replacement may be indicated.79

Given the relatively small apertures in the jejunal tip of the tube, consideration of medications being delivered and formula additives being used is needed to avoid occlusion of the distal tip. It is often best to use the gastric port for medications. Clinical reports of bloating, cramping, and/or significant changes in fecal consistency warrant a review with the dietitian about volumes, rates, and osmolarity of the formula being used.

**Coordination of Oral and Nonoral Feeding Goals**

For some, nonoral feedings are designed to be adjunctive to ongoing oral feedings. Depending on the medical circumstances that resulted in the
RE: Patient’s Name
DO#: 1/1/1111

To Whom It May Concern:
The Pediatric Developmental Disabilities team at Texas Scottish Rite Hospital for Children follows Patient’s Name. Her diagnoses include specific syndrome, severe scoliosis, pectus excavatum with surgical repair x2, multiple cardiac issues, gastroesophageal reflux, asthma, and multiple pneumonias. She underwent gastrostomy placement on Jan 3, 2005, so that she may receive nonoral feedings to help her gain weight and improve her nutritional status in preparation for her upcoming scoliosis surgery.

Her most recent anthropometrics obtained on 1/16/14 were 150 cm (20th percentile/age) and 21.9 kg (<5th percentile/age). Her calculated BMI is 9.7, which is significantly below the 5th percentile for age.

Patient’s Name needs a 1.5 kcal/cc formula to provide maximum calorie intake in minimal volume in addition to her oral feedings. Resource Just for Kids 1.5 w/liter has been well tolerated by the patient. Three boxes daily will provide Patient’s Name 1065 kcal/day (49/kg) to meet approximately 67% of her calorie needs.

Since Patient’s Name is an active child with multiple activities and requires medical appointments, we are requesting an XYZ Feeding Pump. The following reasons outline why this is a unique and clinically necessity for our patient:

1.) Accuracy: The XYZ performs with a +/-5% accuracy with all solutions, across the full flow rate range.

2.) Rate and dose selectivity: The XYZ is the only enteral pump that can deliver nutrition solutions at rates as low as 0.1 ml/hour and as high as 600 ml/hour. It is also the only pump with programmable doses as low as 0.1 mL and as high as 3000 mL. Programming flexibility allows for adjustments to the patient’s therapy as needed.

3.) Battery life: The XYZ twenty-four hour battery life capacity far exceeds any other pump. It is the only pump with a lithium battery. A lightweight battery with long life improves adherence with the needed feeding schedule.

4.) Portability: The XYZ pump and disposable sets allow successful placement in custom packs or tote bags, at the bedside, on strollers, or on wheelchair. The XYZ weighs less than 1 pound (about the weight of a can of soup) and has, by far, the smallest sized carrying pack options for pediatric and adult patients. In addition, the XYZ was designed to operate in any orientation. Many pumps require the use of a drip chamber in their disposable sets. This means they can only operate in the upright position. Patients rarely operate in an upright position. This combination of features enables health-improving physical activity.

5.) Occlusion safety: The XYZ is the only pump with upstream and downstream occlusion sensors to identify back pressure from the gut and clogged tubing. The downstream occlusion sensor is designed to alarm at a lower setting than any other pumps, specifically for the protection of pediatric patients.

6.) Air alarm safety: The XYZ is the only pump with an air detector, which detects air in the line. This protects sensitive patients from the infusion of air, which can lead to painful distention of the stomach or intestines.

7.) Disposable set safety: The XYZ disposable sets are entirely DEHP free and contain an in-line occluder, which will not allow solution to free flow into the patient if it is not loaded properly into the pump.

8.) Cost savings: The XYZ is a rugged pump designed for day-to-day handling. New sensing technology has allowed the pump to be completely sealed so it is the only pump washable under running water. In addition, it does not require annual maintenance/calibration.

9.) Physical, social, and psychological benefits: Based upon its unique feature set, the quality of life of the patient, the family, and caregiver are greatly improved by using the XYZ. The portability and ease of use features of the XYZ remove significant barriers to health-improving physical activity, allowing adults to return to work, and social interaction of patients with friends and family.

We are requesting insurance funding for the following:

(1) XYZ ambulatory feeding pump
(2) IV pole
(3) XYZ 500 ml feeding bags, 30/month
(4) Formula type 1.5 w/liter, 750 ml (3 boxes) daily
(5) Farrell valve gastric relief bags, 30/month
(6) Brand g-button replacement, 2/year
(7) Brand extension sets, 4/month
(8) 60-ML syringes, 5/month
(9) 10-ML syringes, 5/month

Your assistance to the family will be greatly appreciated. If further details are required, please do not hesitate to contact the dietitian at (555) 555-5555.

Sincerely,

Richard C. Adams, MD, FAAP
Wendy Wittenbrook, MA, RD, CSP, LD

FIGURE 3
Sample letter of support to assist families.
need for nonoral feedings, some children will be able to later resume full oral feedings and ultimately remove the gastrostomy button. For these children, the gastrostomy button is placed with plans for its eventual removal. For many children who have complex neurodevelopmental disabilities, the likelihood of the gastrostomy use (solely or in combination with some oral intake) for extended times is high. To the extent that oral-motor coordination skills allow,

<table>
<thead>
<tr>
<th>Diagnosis: Gastrostomy</th>
<th>ALLERGIES:</th>
</tr>
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<tbody>
<tr>
<td>□ Patient receives no po feedings</td>
<td></td>
</tr>
<tr>
<td>□ Patient also receives po feedings (see additional orders)</td>
<td></td>
</tr>
<tr>
<td>□ Tube Feedings</td>
<td></td>
</tr>
<tr>
<td>Formula: ___________________________ (or equivalent)</td>
<td></td>
</tr>
<tr>
<td>Number of daily feedings: ___________________________</td>
<td></td>
</tr>
<tr>
<td>Schedule: ___________________________ (may vary by up 1/2 hour to meet school schedule)</td>
<td></td>
</tr>
<tr>
<td>Amount of formula at each feeding: ___________________________</td>
<td></td>
</tr>
</tbody>
</table>

**Infuse formula via:**

- □ Gravity drip over a period of ____________ minutes
- □ Bolus feed with a syringe over a period of ____________ minutes
- □ Feeding pump at a rate of ____________ ml/hr

**After each feeding,** rinse the G-tube with ____________ ml water

- □ Vent/burp G-tube prior to each feeding.
- □ Use Farrell valve bag during feedings.
- □ Feed ____________ ml water ____________ times daily at ___________________________

**DO NOT check residuals if a child has a gastrostomy button.**

If the tube dislodges or problems occur during feeding, discontinue feedings and notify the parents(s)/Developmental Pediatrics Department at Texas Scottish Rite Hospital.

□ Additional instructions: ___________________________

__________________________
Clinical Dietitian Signature:

__________________________
Physician Signature:

Phone number: ____________ Date: ____________

*FIGURE 4*
Sample letter: orders for school.
oral feeding can assist in dental health, maintenance of feeding skills, enjoyment, and social considerations. Video-fluoroscopy feeding studies (modified barium swallows) are helpful in discriminating between “safe” foods and textures that can be maintained by mouth and “unsafe” textures and foods that place the child at risk for acute or chronic pulmonary conditions. By removing the “high risk” foods, the child can become less defensive (protective) of materials entering the mouth and, thereby, increase the ease and comfort of oral feeding. Repetitive fluoroscopy studies, too often based on arbitrary periodicity schedules, should not be considered a clinical requirement. The radiation exposure from an individual study is acceptable, but frequent or repeated exposures are concerning and should be guided by clinical risk/benefit considerations. Fiber optic endoscopic evaluation of swallowing offers direct visualization of anatomic pharyngeal structures during swallowing, but does not provide information about the oral phase of dysphagia or predict long-term feeding status in children.

Programs focused on establishing “normal” eating behaviors in children can be successful. However, it is important to understand the nature of the programs, their goals and methods, and subject selection (feeding issues among the children treated). For example, in 1 university-based program, the eligible children met specific criteria: resolution or stability of the medical problem causing the need for fundoplication; absence of anatomic or functional impairment precluding safe oral feeding; absence of oral-motor apraxia; maintenance of adequate weight on gastrostomy tube feedings; and/or cognitive/developmental status adequate to allow a response to behavioral therapy sessions. When transition back to full oral feedings is being considered, several questions can help guide the discussion:

- Is the child presently showing adequate growth trends?
- Have oral skills and swallow coordination and safety been recently assessed, preferably by an interdisciplinary dysphagia team?
- Has the medical condition that precipitated the need for the nonoral feeding been corrected or significantly improved?
- Are adequate professional resources (eg, speech therapist with background in feeding children who have disabilities, supports within the school setting, home supports) available to the family in the transition process?
- Are significant child behavioral issues present that could disrupt a transition plan? As the child grows and social constraints of feeding are recognized, psychosupportive therapy may be helpful in this phase of his or her “adjustment to disabilities.” New strategies for coping and interacting with peers and with others in the community may require focused cognitive behavioral therapeutic approaches, especially if the likelihood of nonoral feeding is ongoing.

CONCLUSIONS
The decision to begin nonoral feedings for a child who has acquired or developmental disabilities is complex. Aspects of medical care, cultural values and beliefs (of both the family and the health care professionals), and emotional investments deserve consideration. A commitment to surgery and nonoral feedings involves active dedication by the family, physicians, caregivers, dietitians, social workers, and others involved with the child’s care. This commitment is needed in the process of coming to a decision, taking action on the decision, and especially after a surgical procedure. Optimal function, health, quality of life, safety, comfort, and care should be underlying components driving collaborative plans and support of the child.

RESOURCES FOR MEDICAL HOMES
- http://www.slideshare.net/jessicalynsmith/finalpresentation-13485393. Medical and nutritional management of feeding orders; differential diagnosis and care
- http://www.oley.org/. Oley Foundation; not-for-profit foundation. Information for clinicians, clients, and families
- http://www.cpresearch.org.au/pdfs/pw_tr_Altersatives_to_Oral_Feeding.pdf. Cerebral Palsy Alliance site with focus on nonoral feeding
- http://www.vygon.co.uk/pdf/upload/Enteral_Feedingfull.pdf. Practical care and maintenance of stoma sites and feeding tubes

RESOURCES FOR FAMILIES
- http://www.complexchild.com/. Online magazine written by parents of children who have complex care needs
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Nonoral Feeding for Children and Youth With Developmental or Acquired Disabilities
Richard C. Adams, Ellen Roy Elias and and COUNCIL ON CHILDREN WITH DISABILITIES

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DOI: 10.1542/peds.2014-2829

The online version of this article, along with updated information and services, is located on the World Wide Web at:
/content/early/2014/11/18/peds.2014-2829