



# Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders:

Welcome to Jan 2007! In this issue, we have 2 interesting articles. An excellent research based article from Dr. Ruark on dysphagia management and an introduction to alternative intervention by Dianne Lazer and colleagues. Both articles will be continued in the next issue. As always we have a case, current research, and information on how to search for pediatric feeding literature, a topic inspired by my local peds feeding group.

You may notice that this issue is longer than normal, I had to add 2 pages to fit in our wonderful articles! Easy to do in an email format. Thanks for all those who have sent in working email addresses. Our website is down at the moment but I hope to get it up and running this year. Please feel free to email me with comments, suggestions, and questions! Enjoy, Krisi Brackett [feedingnews@earthlink.net](mailto:feedingnews@earthlink.net)

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## Part 1: Best Practices for Behavioral Management of Pediatric Dysphagia by Jacki Ruark McMurtrey, Ph.D., CCC/SLP, Univ of Central Arkansas, [jackir@uca.edu](mailto:jackir@uca.edu)

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There is clinical evidence that services provided by swallowing clinicians benefit pediatric patients with dysphagia. Consistent with the framework of the World Health Organization, intervention for pediatric dysphagia should address the following: (1) inadequate nutrition and hydration, (2) risk of pulmonary complications, (3) discoordinated movements of the oropharyngeal mechanism and respiratory system, and (4) behavioral and sensory issues that interfere with swallowing. Before children with dysphagia can be provided with the most effective, efficient, and safe treatment, the anatomical and/or physiological reason(s) for their swallowing disorder need to be identified (Logemann, 2000). This means that in many cases, children with suspecting dysphagia will need further diagnostic testing beyond the initial clinical swallow examination. In addition, therapeutic techniques should be attempted during an instrumental swallow evaluation (sparingly) when it is anticipated that a technique will promote a safe swallow (Arvedson & Lefton-Greif, 1998).

Management for pediatric dysphagia may be classified as either surgical (e.g., feeding tube placement, cricopharyngeal myotomy) or behavioral. Behavioral management of pediatric dysphagia includes using compensatory strategies to modify the environment (e.g., changing bolus characteristics), or rehabilitative, such as teaching a child how to perform oral motor exercises to improve muscle strength. Compensatory strategies have an immediate, but temporary effect on swallow safety; rehabilitative strategies may promote a long-term effect and change the physiology of the swallow. Many times compensatory and rehabilitative techniques are used concurrently when treating children with dysphagia. When deciding which behavioral techniques are most appropriate for our pediatric clients, several factors must be considered, such as a child's level of alertness and interactiveness, age and cognitive ability, receptive ability, and capacity for compliance (Newman, 2000). For example, the swallowing clinician must take into account that

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**Special Points of Interest:**

- ☉ Current information
- ☉ New products
- ☉ Research and publications
- ☉ Education

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Inside this issue:		
Management of Pediatric Dysphagia	Pe-	1-5
How to do a Peds Feeding lit review		5
Addressing Feeding Problems Holistically		6-9
Case by case		10-11
On the Research Front		12



# Best Practices for Behavioral Management of Pediatric Dysphagia

By Jacki Ruark McMurtrey, Ph.D., CCC/SLP, Univ of Central Arkansas, jackir@uca.edu

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young children may not be able to learn swallowing maneuvers, and children may not comply with postural variations. However, older children, depending on cognitive, receptive, and motoric abilities, may be able to perform various techniques and maneuvers used by adults with dysphagia (Newman, 2000).

One question frequently asked by swallowing clinicians is: "How do we determine which behavioral strategies will help our clients become safe swallowers?" ASHA's answer to this question is that clinicians should incorporate the principles of evidence-based practice in clinical decision making to provide the highest quality of care (ASHA 2004). Evidence-based practice simply means integrating our clinical expertise with evidence from systematic research. One can use the principles of evidence-based practice to determine the best practice for implementing treatment strategies with children who have dysphagia, such as determining the best practice for altering postural alignment, changing the bolus texture in a child's diet, or providing sensory enhancement techniques. For the purpose of this article, a literature search was conducted on behavioral treatment techniques used to treat pediatric swallowing disorders using: electronic databases (e.g., Cochrane Library, PubMed, CINHL, PsychInfo), conducting manual searches (e.g., reviewing book and article references), and reviewing book chapters. The literature searched focused on specific behavioral techniques used to treat children with dysphagia who are oral feeders. (Note: not all behavioral techniques used with the pediatric population are discussed in this article as literature to support such techniques was limited).

## *Compensatory treatment strategies: Positioning/postural alignment*

There is empirical evidence that altering the position of a child with dysphagia during feeding has a positive effect on swallowing. The literature review revealed that changing the position of a child is the most common compensatory strategy used to enhance optimal feeding patterns in children. Postural variations of the body/head/neck alter the relationship of structures within the oropharyngeal cavity and affect the control and flow of the bolus. Larnert & Ekberg (1995) studied 5 children with quadriplegia and dystonia who were severely, motorically involved. Each child swallowed 3 ml. boluses of barium puree and an uncontrolled amount of liquid barium from a cup during two separate videofluoroscopy procedures. The children were positioned upright during the initial procedure and were reclined 30 degrees with neck flexion (via a pillow) during the second procedure. The results of the study revealed that two of the five children showed decreased premature spillage with head/neck flexion/reclined position. The authors, however, did not report which bolus size (3 ml. bolus vs. a bolus of uncontrolled amount) promoted less premature spillage, or whether those children who continued to exhibit spillage, had more difficulty controlling the larger size bolus. In addition, four of the five children demonstrated a decrease in aspiration when swallowing pureed with head/ neck flexion, and all participants demonstrated a decrease in aspiration when swallowing liquids.

Head and neck postures mentioned in the pediatric literature mainly include the following: (1) chin tuck, (2) head rotation to weak side, and (3) tilting head to strong side. The chin tuck position is used when there is a delay in the pharyngeal swallow or a decrease in airway protection (chin tuck reduces closure of airway entrance). The chin tuck position, however, is inappropriate to use with young infants due to the possibility that their pharyngeal structures may collapse. The effects of head/neck positions on bolus flow and control should always be confirmed via diagnostic testing. As with adults, head and neck postures are not always effective in treating swallowing disorders in children and may in fact have a negative effect on swallowing. In addition, children need to be monitored during eating to ensure compliance with the selected head and neck posture throughout a meal.

In another investigation regarding positioning, Hulme & colleagues (1987) found that children with cerebral palsy (mean age = 3 years) benefit from using an alternate seating device (ASD) during meals. The authors found that the best position for the children in this investigation included: vertical head position, upright trunk, hips flexed at greater than 90 degrees, knees flexed at 90 degrees, ankles in neutral or slight dorsiflexion position, and feet supported on a flat surface. This position allowed many children in the investigation to advance to a thicker consistency during feeding, and progress from bottle to cup drinking. The investigators also found that altering the position of participants in their study had no significant effect on oromotor control (lip and jaw movements) during feeds. In another study regarding ASDs, Reilly & Skuse (1992) found that 50% of parents in a home base study placed their child in an adaptive seating device during meal time and 50% considered the equipment a nuisance. These caregivers found it easier to position their child on a couch or in their lap. As swallowing clinicians, we must keep in mind, that each child should be evaluated individually to determine their best feeding position, and the position adopted for meal times should take into account a child's communication needs and the feeder's comfort (Reilly & Skuse, 1992).

## *Altering bolus consistency*

Another common behavioral technique used to treat pediatric dysphagia is modifying a child's diet to enhance the efficiency

## Best Practices for Behavioral Management of Pediatric Dysphagia

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and safety of their swallow. Review of the literature indicated that the effects of altering bolus consistency to improve swallowing in children with dysphagia have yet to be investigated systematically. However, research investigations that characterized dysphagia within specific pediatric populations (e.g., children with cerebral palsy) recommended diet modifications as part of the treatment regime for their participants (e.g., Rogers, et al., 1994; Leder & Karas, 2000). Several investigations have revealed some challenges in determining the best/safe consistencies for pediatric clients. Tcheremenska & Gisel (1993) found that children with cerebral palsy take significantly longer durations to orally manipulate and swallow apple sauce (“less viscous”) vs. pudding boluses (“more viscous”). This finding suggests that food substances that appear to be similar in consistency (i.e., apple sauce and pudding are considered puree) may in fact effect swallowing differently in children with swallowing disorders. In addition, the results of the study suggest that it may be easier for children with feeding disorders to manipulate more cohesive boluses (i.e., pudding) than boluses of thinner textures (i.e., apple sauce). In another investigation, Gisel & colleagues (e.g., 1988) found that in typically developing children, the ability to orally manipulate or chew solid boluses is mastered earlier in development than the ability to orally manipulate purees. For example, after children turned 6 years of age, there was no significant difference in the time (in seconds) it took the children to chew a solid bolus when compared to older children. Thus, the ability to chew a solid bolus efficiently was deemed to be mastered by 6 years of age. The interpretation of findings in this investigation has lead some individuals to suggest that children with swallowing disorders may handle solid foods easier and more safer than puree, which may be true in some cases. However, the study by Gisel and colleagues focused on typically developing children, and the oral preparatory phase of swallowing was the only focal point of the investigation (e.g., as compared to pharyngeal components).

In adults, changing the consistency of a bolus may affect swallowing in several ways, such as altering the duration of oral-pharyngeal transit time and increasing lingual pressure and pharyngeal contractions during swallowing (e.g., Bisch et al., 1994). In a study on typically developing children, Ruark and colleagues (2002) found that boluses of thicker consistency require longer duration and amplitude of muscle activity during swallowing in 5-year-old children. In a similar investigation, boluses that appeared to be similar in consistency (e.g., liquid barium *vs.* water) yield significantly different swallowing patterns (i.e., liquid barium increased multiple swallowing activity) (Ruark et al., 2003). Thus, when selecting the most appropriate food consistencies for pediatric patients with dysphagia, the selection process needs to be child-specific. Each child should be treated individually, and the swallowing clinician should take into account several factors regarding their client. For example, the clinician must decide if a child is prepared physiologically for a particular food consistency (rather than chronologically), and determine which food consistencies can be swallowed with adequate airway protection and clearance.

### *Bolus volume*

Review of the pediatric swallowing literature indicated that, in general, providing pediatric patients with small size boluses is encouraged. Larger boluses, however, may enhance oral control in some children with sensory issues (e.g., those who have difficulty sensing that a bolus in their oral cavity). When presenting a child with dysphagia with a large size boluses, the swallowing clinician should determine whether the bolus can be swallowed safely (e.g., their client has adequate airway protection). In all, the optimal size of a bolus should take into account texture differences (e.g., thinner boluses may be presented in smaller volumes). In typically developing children, larger boluses have been found to yield multiple swallowing activity. For example, children may produce two-three swallows when given a 10 ml bolus of water in comparison to a 5 ml bolus of water. This finding suggests that swallowing clinicians should be cautious when presenting children with dysphagia with larger size boluses; the size of the bolus may stress the swallowing system in that it requires multiple swallows in order to clear their oral and pharyngeal cavities (which may be difficult for some children with dysphagia to perform).

### *Sensory enhancement techniques*

Other compensatory management modalities used to treat children with dysphagia include sensory enhancement techniques. These techniques provide increased oral sensory input and may enhance bolus preparation for swallowing in children with dysphagia. Studies that have focused on the effects of sensory enhancement techniques on pediatric dysphagia are limited in number. Review of the literature suggests that a child’s reaction to sensory techniques should be closely monitored to determine which technique facilitates swallowing. Some children demonstrate hyporeactive responses to oral sensory input such as diminished responses to taste, temperature, and/or touch (Arvedson, 2002). Swallowing in these children may be enhanced (bolus formation may improve; oral transit time may decrease) if they are presented with larger boluses, and/or more textured boluses. Other children may demonstrate hyper-reactive responses to sensory input which are exaggerated responses to taste, temperature, and touch. These children may demonstrate more efficient and safe swallowing when presented with less textured boluses and/or boluses that are smaller in volume. Providing a cold bolus may improve oral transit in some children. However, children with dysphagia may also dem-

## Best Practices for Behavioral Management of Pediatric Dysphagia

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onstrate an aversive reaction to cold liquid or food, and more room temperature or warm boluses should be presented (Arvedson, 1998). Alternating boluses of varying temperature is also described in the literature where a child may be presented with a chilled bolus prior to a room temperature, or warm bolus. The goal of this sensory enhancement technique is to use the cold bolus to alert the central nervous system that a bolus is present in the oral cavity and a swallow is needed. The influence of the cold bolus in making a swallow more efficient will hopefully carryover to the next bolus presented (which may be a bolus that is not chilled).

One study that investigated the effects of thermal stimulation on swallowing in children was conducted by Helfrich-Miller & colleagues (1986). These investigators studied six profoundly disabled individuals with cerebral palsy; two of the participants were children (ages 10 & 12 years of age). Baseline data regarding the participants' swallowing abilities were obtained via videofluoroscopy, an ENT examination, and an oral mechanism examination. Measures were repeated at three, 4 month intervals. Findings from the initial base-line examinations revealed that two of the six participants aspirated paste consistency; all exhibited a delayed swallow reflex, pharyngeal residue, and multiple swallows per bolus. The participants were provided with a treatment program which included a combination of thermal stimulation (i.e., cold stimulation via laryngeal mirror provided to the anterior faucial pillars), oral motor treatment, and diet modifications. This treatment protocol was provided three times per day, seven days per week before each meal, for a 12 month period. There were four phases to the study. After 4 months of treatment (end of Phase I), repeat examinations revealed that only one participant aspirated, three/six participants showed decreased pharyngeal transit time, and five demonstrated decreased pharyngeal residue. After 8 months of treatment (end of Phase II), the participants continued to show improvement in all problem areas (e.g., aspiration became non-existent, residue and multiple swallows decreased). After 12 months of treatment (end of Phase III: Withdrawal phase), thermal stimulation was discontinued for three participants which lead to a regression in the pharyngeal swallow function in two of these individuals (i.e., increase pharyngeal transit time). Three additional participants continued to receive thermal stimulation to elicit a safer swallow. The authors of the study did not provide any information regarding the long-term effects of thermal stimulation on swallowing in these participants. The findings of this study indicate that the combination of treatment (thermal stimulation, oral motor therapy and diet modification) improved swallowing in individuals with dysphagia, including children. The long-term carryover effects of thermal stimulation on improving the efficiency and safety of swallowing was not evident in this investigation

### *Taste*

Taste is another sensory enhancement technique that is used to enhance swallowing in children with dysphagia. However, the physiological affects of taste on swallowing in children is unknown. Review of the literature revealed that the development of taste perception begins in utero and continues until late adolescence. At birth, infants show a preference for sweet tastes and an aversion to bitterness (Desour et al., 1973). Preference for saltiness is neutral or aversive, and adult-like responses appear at approximately two years of age (Crook & Lipsitt, 1976; Lawless, 1986). Sour tastes are rejected at birth and are less accepted in older infants and toddlers, e.g., 12-24 months (Mennella, 1997). Taste preferences and sensitivity of older children also differ from adults'. Children have heightened preferences for sweet, salty, and sour tastes (Liem, 2003) and demonstrate a greater sensitivity to certain tastes than adults (e.g., sweet).

The taste preferences of children with dysphagia may differ according to the child. Strong flavors may improve the oral motor abilities and swallow physiology in some children; others reject strong flavors and prefer foods that are mild (Arvedson, 1998). The impact of taste deprivation on food and flavor acceptance in children with dysphagia is an important area for research. Children who are safe oral feeders should be presented with a range of tastes. The importance of providing a variety of flavors during the weaning process has been demonstrated in typically developing infants (Reau, 1996). Research has also shown that transition from milk to a mixed diet is facilitated by providing infants with bridges of taste familiarity (Mennella & Beauchamp, 1997).

Using a sour bolus to enhance swallowing has been investigated in adults. For example, Ding and colleagues (2003) found that when adults with dysphagia are presented with high concentrations of citric acid, the timing of the swallow improves significantly. Participants in their investigation, however, found the boluses to be unpalatable. Pelletier and Lawless (2003) investigated the effects of both palatable boluses (1.1% w/v citric acid-8% w/v sucrose mixture) and non-palatable boluses (2.7% w/v citric acid-deionized water bolus) on swallowing in participants with dysphagia. The swallow in these individuals improved significantly when given the unpalatable boluses. The more palatable bolus, however did not have a significant effect on swallowing. Thus, the use of sour boluses to enhance the physiology of swallowing in children with dysphagia is questionable, as children are less likely to consume high concentration of citric acid. Sour boluses are also quite dangerous to present to children with dysphagia due to the possibility of aspiration of citric content.



## Best Practices for Behavioral Management of Pediatric Dysphagia

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*Pacing:* Pacing is a compensatory strategy that is used with children with dysphagia to adjust the time interval between bolus presentations (e.g., between swallows). This technique is used when additional time is needed in order for the child to produce a safe swallow. Pacing the bolus presentation, however, may increase the duration of meals. Therefore, caregivers need to balance pacing techniques with the total time to feed a child. Mealtimes in excess of 25-30 minutes results in children expending excessive energy during oral intake. In this case, children with dysphagia may receive additional meals (where bolus presentations are also paced) that last for shorter lengths of time. Children may also receive supplemental feedings to counteract time needed to complete meals.

Review of the literature revealed one study that investigated the effects of pacing on swallowing in children. Pinnington and Hegarty (2000) found that presenting food in a consistent manner with optimal positioning improves feeding skills in children with severe motoric and neurologic impairments. In this investigation, children with cerebral palsy, ages 7-17 years, were presented with food items via a self-activated, mechanically controlled robotic arm for a period of three months. The children's oral motor behaviors (as measured by the Schedule for Oral Motor Assessment) and postural control during eating (when using the mechanical feeding device) were compared to these same behaviors when the children were fed by caregivers. Results revealed that the mechanical feeding technique allowed the children to take a more active role in the feeding process which lead to improvements in the range and control of their lip and jaw movements. Using the mechanical robotic arm also gave the children greater opportunity to prepare for upcoming bolus presentations (as they self-activated the robotic arm), and did not lead to meals that were longer in duration (as compared to being fed by caregivers). This investigation demonstrated that children with cerebral palsy can be safe self-feeders. Children with motoric impairments may benefit from the additional time it takes to receive a bolus (due to time needed for hand-to-mouth coordination). Children who are self-feeders may also be more aware (versus a caregiver) when they are ready to receive another bolus based on food clearance. In addition, other research has found that self-feeding techniques may have positive effects on the coordination of breathing and swallowing in children with cerebral palsy (e.g., McPherson et al., 1992).

**\*(This article will be continued in our next issue: April 2007)\* \***

**How to search for pediatric feeding research: Searching for pediatric feeding/swallowing articles is challenging because there is not one specific journal to read. Because of the complicated nature of feeding disorders, a thorough search of many topics and journals is required.**

1. You can search through several search engines (here are a few). I usually put limits on my search such as "0- 18 years of age", or "English text"

**Pub Med:**

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?CMD=Limits&DB=pubmed>

**Infotrieve:** <http://www4.infotrieve.com/newmedline/search.asp>

**EBSCOHOST:** accessed through a university library. It is a wonderful search engine that allows you to select and search many different databases at one time (Medline, Eric, Academic Search Elite, PsychInfo, etc...) If you can access it, you can click all the databases that you want to search (and full text if you wish) and it will do the work of searching them all at once.

2. I use a variety of key words to look for articles

**search words:** pediatric feeding, pediatric dysphagia, swallowing, appetite, oral motor, failure to thrive, gastroesophageal reflux Drooling, food refusal, food selectivity, behavioral feeding, sensory feeding, allergy, nutrition and feeding disorder, constipation, suck, sucking, can search by diagnosis, researcher, or setting.

## Addressing Feeding Problems Holistically: An Integrative and Nutritional Team Approach (A Two Part Series) by Dianne Lazer, MA, CCC-SLP/COM, Lic. SLP/Certified Orofacial Myologist, Mary K. Grinovics, OTR/L, OT/L, Mitch Plotnick, Certified Holistic Health and Nutrition Counselor

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We all agree that successful feeding intervention is benefited by an interdisciplinary approach that often includes a wide range of medical specialists (GI, ENT, Pediatricians, Nursing, Dieticians, OT, PT, SLP, etc). Although this may be a good base in which to start the assessment process, we have begun to see even greater benefits from a more integrative medical approach that includes consultations with chiropractic and naturopathic practitioners who may offer additional insight into the “more difficult to manage” patients and help the traditional interdisciplinary treatment team overcome obstacles often encountered in this population.



What is integrative medicine? Integrative medicine attempts to combine the best ideas and practices of conventional and alternative medicine. It works from the premise that the body can heal itself if given a chance. Practitioners of integrative medicine try to learn and teach about natural methods that promote healing including dietary change, stress reduction, use of herbal remedies, etc. (Weil,1999).

Of the many types of integrative practitioners, the chiropractor and naturopathic doctor may offer some surprising benefits to your feeding management patients. For example, some of the most common and frustrating medical issues we have found impacting the feeding management process for our patients are chronic congestion, ear infections, reflux, asthma and voice disorders. Sending patients out for ENT and GI consultations often sets into motion the traditional medical model response of giving antibiotics, histamine blocking agents, acid and proton pump inhibitors and placement of myringotomy tubes. Although, at first glance, these medications and interventions may help the patient’s initial problems, many of these treatments may have side affects that negatively affect the child’s upper respiratory and/or gastrointestinal systems in the long term and do not remedy the underlying cause of the patient’s illness.

Taking an integrative medicine approach, however, uncovers a wide variety of alternative therapy options that may better suit our population and help heal the gut and other difficulties much more effectively.

One therapy we have found to be helpful in our practice is *Applied Kinesio Muscle Testing* for allergies and food sensitivities. The International College of Applied Kinesiology defines this approach as the evaluation of normal and abnormal body function by testing the strength of corresponding muscle groups ([www.icakusa.com/general.html](http://www.icakusa.com/general.html)). It was originally developed in the 1960’s by Dr. George Goodheart and has since broadened to include evaluation of the nervous, vascular and lymphatic systems, and nutrition, acupuncture and cerebrospinal fluid.

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To apply this methodology for determining food sensitivities, a skilled practitioner tests a particular muscle or group of muscles for strength of contraction and places a small amount of a suspected offending food on the tongue of the patient, then re-tests that same group of muscles. If the food introduced is poorly tolerated by that individual, the quality of the muscle contraction is diminished. We have found this quick and non-invasive method of determining food sensitivities to be very helpful. Those patients who have made dietary changes based on its findings have benefited greatly and demonstrated fewer symptoms related to their specific food intolerances.

Birth trauma and use of forceps may also be an overlooked factor for many of our younger patients. Use of forceps can result in subtle (and sometimes not so subtle) skeletal misalignments, which can result in reduced sucking and feeding issues, particularly for infants in the early weeks and months of life. In these cases we have found *CranioSacral therapy* techniques to be highly effective.

CranioSacral Therapy (CST) is a gentle, hands on method of evaluating and enhancing the functioning of the physiological body system called the craniosacral system. It is comprised of the membranes and cerebrospinal fluid that surround and protect the brain and spinal cord as well as the attached bones (including the skull, face and mouth which make up the cranium), and the tailbone area or sacrum. CST was pioneered and developed by osteopathic physician John E. Upledger following extensive scientific studies from 1975–1983 at Michigan State University, where he served as a clinical researcher and Professor of Biomechanics.

Using a soft touch generally no greater than 5 grams, or about the weight of a nickel, practitioners release restrictions in the craniosacral system to improve the functioning of the nervous system, enhancing the body's natural healing capabilities. Since the brain and spinal chord are integral components of the central nervous system, it is easy to see that the craniosacral system has powerful influence over a wide variety of bodily functions. For nearly 30 years, it has been shown to be very effective for a wide range of medical problems associated with pain and or loss of function including headaches, neck and back pain, motor-coordination impairments, colic, autism, central nervous system disorders, orthopedic problems, scoliosis, TMJ, neurovascular or immune disorders, etc. (Baumgardner, 2006).

Another factor interfering with successful feeding management treatment is the *American diet*. Many of our patients just cannot tolerate the high amounts of simple carbohydrates, dairy and processed foods that make up an average child's diet these days. The clinical symptoms we see over and over again are chronic congestion, eczema, fatigue, poor weight gain, food selectivity and picky eaters, behavioral and emotional dis-regulation issues and countless others that make our head spin. A perfect example of this is a two-year old boy who was seen at our center for a speech/language/feeding evaluation with a medical history of chronic ear infections and myringotomy tube placement at 18 months. Upon re-view of his daily diet, it was noted that he only ate processed carbs, dairy and juice. Before any tradi-

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tional “speech, language and or feeding therapy” can begin, it is our opinion that this child should be referred for a nutritional assessment with a specialist knowledgeable in improving the child’s diet and who will make recommendations to the parents on how to carry this out effectively. That is often more easily said than done. However, we have found much success in our practice working closely with naturopathic doctors, integrative nutritionists and holistic nutrition counselors who understand the difference between two major food allergy concepts: immediate-response allergies and delayed-response allergies.

Kelly Dorfman, MS, LN, in her article that originally appeared in the Great Plains Laboratory, Inc. Health, Metabolism and Nutrition Newsletter, 1999, and appears on their website today, defines allergies as specific reactions within the immune system involving an antibody called immunoglobulin E (IgE). She further notes that immediate responses such as hives, congestion or swelling typically result from IgE activity. IgE testing identifies triggers such as pollen or peanuts which can cause symptoms that range from annoying to lethal. On the other hand, Dorfman also reports that patients can also have responses that occur more than two hours after eating food that may result from immunoglobulin G (IgG) rather than IgE activity. She says that IgG reactions may cause symptoms such as sleep disturbances, sinus and ear infections and overall crankiness. Blood tests rather than scratch tests are the only way to screen for IgG allergies and we have found the naturopathic doctor or integrative medical professional is very helpful in administering this blood test and helping to detect if patients have a delayed response to particular foods.

***We have also found it helpful to refer to nutrition counselors who understand the importance of a customized approach to dietary changes.***

In her book titled “The Self-Healing Cookbook,” author Kristina Turner explains that “the body naturally seeks balance,” and that “all illness stems from imbalance.”

Eating an excess of dairy, sugar, salt, processed carbohydrates or unhealthy fats can easily lead a person’s body out of balance. The same is true if a person eats just a relatively small amount of food to which they are allergic or sensitive. ***In either case, the symptoms that can result from food-triggered imbalance in the body include excess mucus and congestion, headaches, digestive tract ailments, high blood sugar levels, emotional disorders and many more.***

The cutting-edge movement in holistic health and nutrition is “bio-individuality.” This emphasizes the importance of taking into account a person’s health status and history, along with their unique body chemistry, lifestyle and preferences. Indeed, each person’s health and nutrition picture is as unique as their fingerprint.



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By working with the individual at that customized level, the holistic nutrition counselor can provide well-suited strategies that enable a person to change their relationship with food. These strategies often involve trying alternatives to the imbalance triggers, so a person can get both the nutrients and enjoyment they need from food, while allowing their body to heal and find its balance.

However, it is important that the patient be *gently guided* and monitored while transitioning from volatile foods to the healthier, balancing options. For example, sugar is an addictive substance, and therefore withdrawal symptoms can result from sudden sugar abstinence. Also, without guidance, a patient might elect to switch from sugar to artificial sweeteners, which many experts view as unhealthy and unacceptable alternatives. Finally, this gentle transition is essential also because it helps ensure sustainable change.

It is our belief that those of us who specialize in the pediatric feeding and dysphagia field need to be cognizant of the whole patient particularly when it comes to the foods we eat. Dairy, sugar and processed foods can be our worst enemy, but many of us overlook this basic nutritional component as “an accepted way of life” in our society today. While traditional medical approaches to feeding problems are valuable, the addition of alternative therapies may help us form a more comprehensive approach that strengthens the practitioner's ability to achieve more successful results with our pediatric patients. Indeed, this broader *integrative* approach also gives us a wide range of tools for treating our patients and uncovering the underlying cause of their illnesses.

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# Case by Case: Poor intake and poor weight gain



## **Feeding Evaluation**

Name: M

DOB: 10/26/04, 24 months

## **Medical Diagnosis:**

1. Down's Syndrome
2. Feeding difficulty (poor intake, nutrition comes from Bright Beginnings soy formula) Poor weight gain

## **Medical History:**

**Birth History:** M was the 7 lb, 10 oz. product of a full term gestation. He had difficulty nursing initially and used an NG tube for nutrition. He was transitioned to the bottle and was discharged on bottle feedings.

**ENT/ Pulmonary History:** There is no pulmonary history . M had PE tubes placed at 6 months. Hearing function is WNL.

**GI History:** M has a history of spitting up multiple times per day with Lipel during the first year of his life. Around 1 year, he was put on soy milk. Mom reported that around 1 ½ , M had a bad GI illness with severe vomiting that lasted about 24 hours (after this he refused cup drinking). At approximately 22 months, he had diarrhea. He has weighed 23 lbs since 1 year of age. At the doctors, he was switched to Bright Beginnings soy formula to increase calories and nutritional intake. From the age of 1 until 2 years of age he has eliminated foods from his diet. Presently, he takes formula and refuses more than tastes of foods. He does not demonstrate vomiting, gagging, or regurgitation currently. He does show volume limiting, food refusal, oral aversion, and coughing at night.

**Development History:** Developmentally, he sat at 9 months, crawls, and pulls to stand. He does not walk. He communicates verbally and with sign.

**Nutrition/ Growth history:** Weight = around 23.2 lbs. Length = 32 ¼ inches. M is followed by GI/nutrition. Mom reports that he has not gained weight in 1 year.

**Feeding History:** M was bottle fed breast milk and Lipel for the first month. He took Lipel until approximately one year. He has reported daily spit ups. By 6 months, he loved food and was progressing well with eating. He liked textures and spicy foods. At one year, he became more picky. He was switched to soy milk. He preferred pea soup and yogurt. By 2 years of age, M was refusing textures except for a few cheerios and spitting food out. He receives all nutrition from Bright Beginnings soy formula.

**Current Feeding:** Currently, M takes between 3 –4 cans of Bright Beginning Soy formula per day. He drinks 4 – 6 ounces per feeding although at night he will take 8 ounces. He is offered 3 -6 foods multiple times per day. He may take a few tastes, spit it out or refuse bites totally. He will self feed a few cheerios. He may bite on a cheerio and then spit it out.

**Oral-Motor Exam:** Based on observation:

**Jaw (CNV):** WNL

**Facial (CNVII):** Observed symmetrical smile, opening, and closing. Mildly low tone

and strength.

**Lingual (CNXII):** protrudes midline, lateral movement with biting.

**Palatal/laryngeal (CN IX, X, XI):** Did not test gag. Clear vocal quality.

**Observation of eating:** M was positioned in a highchair at the kitchen table. His mother offered him baby food chicken, banana, and cheerios. He refused the baby food by saying "no" and pushing the spoon away.

## Case by Case:

One time, he licked the spoon and threw it. He self fed one cheerio and demonstrated lateral biting but refused any more. A few minutes later, Dad was able to give him a few tastes which he spit out.

**Assessment:** M is a 24 month old male with Down's syndrome who presents with a severe disorder characterized by dependence on formula for nutrition, poor weight gain and growth, and total food refusal:

1. **Oral Motor:** Normal structures but low tone and immature oral motor pattern (midline pattern with emerging chewing skills).
2. **Swallowing:** No clinical signs of swallowing difficulty reported.
3. **Respiration:** WNL.
4. **Gastrointestinal Issues:** (may effect feeding) history of GER/spitting the first year of life, recent episode of diarrhea, oral aversion, food refusal, volume limiting with liquids, slow/poor weight gain, coughing at night, maternal grandmother has a history of difficulty with dairy as well as diagnosis of Down's syndrome and possible tendency toward motility problems.
5. **Motor:** Delayed motor skills, slightly out of postural alignment. Sits well but uses posterior pelvic tilt.
6. **Nutrition:** On Downs's chart, M plots around the 25<sup>th</sup>-50<sup>th</sup>%ile for weight and between the 50<sup>th</sup>-75%ile for height. Parents report that he has been the same weight since one year of age.
7. **Behavior:** Demonstrates aversive feeding behavior (food refusal, spitting food out, verbally refusing food, pushing spoon away).

### Recommendations:

1. **Medical:** Consider GI management/intervention to assist with oral acceptance of solids. Consider trial of an acid blockade to determine if it decreases coughing at night and oral aversion. M may benefit from a prokinetic or appetite stimulant as well as an allergy test or further GI work up to assess motility/allergy.
2. **Nutrition:** Consult with dietician for accurate calorie needs. It appears that M is 10.5 kilos and is receiving about 1000 calories per day from formula with poor weight gain. He may need more calories for growth. It is recommended that M's parents be given a calorie goal.
3. **Motor:** Continue to work on improving trunk control and strength for postural alignment.
4. **Behavioral feeding therapy:** after GI intervention, M may benefit from a structured behavioral feeding program to increase acceptance of solids.
5. **Oral-motor:** After M's acceptance of food improves, therapy can assist with improving oral motor pattern.

**Update:** 2 months later: M is on 15 mg of Prevacid daily, RAST testing WNL. Using GI management plus a basic behavioral feeding approach (distraction while accepting/no reinforcement for refusal), M is taking 6—10 oz. of puree for 4 feeds per day. He is drinking 15-18 oz. of Bright Beginnings per day. Parents were asked to limit meals to 7 oz because of reflux with large volumes.

Goals include: good positioning for feeding, weight gain, use of a mature oral motor chewing pattern, and self feeding. M has an endoscopy pending to evaluate for esophagitis, allergic esophagitis, and celiac disease.

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## On the Research Front:

**Valicenti-McDermott M, McVicar K, Rapin I, Wershil BK, Cohen H, Shinnar S. (2006) Relationship of Dietary Intake to Gastrointestinal Symptoms in Children with Autistic Spectrum Disorders. J Dev Behav Pediatr. Apr;27(2 Suppl):S128-36.**

This study compares prevalence of GI symptoms in children with autistic spectrum disorders (ASDs) and children with typical development and with other developmental disabilities (DDs) and examines the association of GI symptoms with a family history of autoimmune disease. A history of GI symptoms was elicited in 70% of children with ASD compared with 28% of children with typical development and 42% of children with DD. Abnormal stool pattern was more common in children with ASD (18%) than controls (typical development: 4%, DD: 2%). Food selectivity was also higher in children with ASD (60%) compared with those with typical development (22%) and DD (36%). Children with ASD have a higher rate of GI symptoms than children with either typical development or other DDs. In this study, there was no association between a family history of autoimmune disease and GI symptoms in children with ASD.

**Mousa H, Caniano DA, Alhajj M, Gibson L, Di Lorenzo C, Binkowitz L. (2006) Effect of Nissen fundoplication on gastric motor and sensory functions. J Pediatr Gastroenterol Nutr. Aug;43(2):185-9**

Bloating, abdominal pain, and early satiety have been reported in up to 30% of patients after Nissen fundoplication. The authors hypothesized that these complications are linked to either the effects of surgery on gastric sensation, compliance or motor function or to preexisting physiological abnormalities. After fundoplication, patients had significantly higher minimal distending pressure values, reduced gastric compliance and significantly higher pain scores. Presurgery and postsurgery gastric emptying at 60, 90 and 120 minutes after feeding showed no significant changes. After Nissen fundoplication, children with gastroesophageal reflux manifest the following: (1) reduction in gastric compliance, (2) increase in minimal gastric distending pressure, (3) exacerbation of the sensations discomfort with gastric distension and (4) no effect on gastric emptying.