



# Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders,

Welcome to Volume 6! In this issue, we've packed articles about food chaining, hyperinsulism and stooling patterns. Check out the new research and case study (which involves a set of circumstances resulting in a quick transition off of a g-tube). We also tell you about a free nutrition reference book from Nestle.

Thanks for coming back, Krisi Brackett MS SLP/CCC

**Pediatric Feeding and  
Dysphagia Newsletter**  
Hiro Publishing  
[www.feedingnews.com](http://www.feedingnews.com)

Volume 6, number 1

July, 2005

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## Food Chaining Programs: Multidisciplinary Treatment of Feeding Aversion in Children

by Mark Fishbein, MD, Sibyl Cox, RD SIU School of Medicine, Springfield, Illinois, Laura Walbert and Cheri Fraker CCC-SLP, CLC Preemietalk, Springfield, Illinois

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Feeding is not only a natural part of life, but also a vital part of life. Without the ability to meet our nutritional needs in some way, our life is in jeopardy. Children progress through the different feeding stages, mastering each one from bottle or breastfeeding all the way to consuming solid foods. However, some children struggle with feeding skills from their first day of life or there is a problem during the developmental feeding progression. Feeding disorders occur with a reported incidence of minor feeding problems ranging between 25% and 35% in normal children and with more severe feeding problems observed in 40% to 70% in infants born prematurely or children with chronic medical conditions (Rudolph and Link, 2002).

Many of these children have been referred for traditional rehabilitation services for evaluation and treatment. However, the complexity of the disorder often requires multidisciplinary, specialized care from a pediatric feeding team for a successful outcome. Optimally, the team should include the disciplines of speech pathology, occupational therapy, psychology, nutrition, gastroenterology and otolaryngology for the core evaluation. Additional evaluation and support from specialists in radiology, social services, child life, neurology and pulmonary medicine is often used. Interdisciplinary evaluation facilitates integration of expertise from different disciplines to provide insight into the various factors that interact in contributing to the child's feeding /swallowing disorder and overall health. Many children have already developed feeding disorders that are highly resistant to intervention. This article will present an alternative approach to traditional intervention programs.

### Pre-Chaining and Food Chaining© Programs

Treatment programs must become pro-active in implementing preventative care programs for at risk or medically fragile children. Programs should be designed to prevent feeding problems from developing or to preserve existing feeding skills. The novel techniques of Pre-chaining© and Food Chaining © (Fraker/Walbert/Cox) have been developed as an additional method of treatment when working with children with or at risk for developing feeding aversion or severe food selectivity.

Pre-chaining programs are developed to prevent aversive response to oral input and develop or maintain oral skills. These programs keep the high-risk child as close to the developmental progression of oral skills as possible especially during the critical

*(Continued on page 2)*

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### Special Points of Interest:

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

Editorial assistance provided by Elizabeth Crais Ph.D. CCC SLP, Division of Speech and Hearing Sciences, UNC-Chapel Hill and Cathy Fox MS OTR/L, Private Practice, Frederick, MD

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# Food Chaining Programs: Multidisciplinary Treatment of Feeding

**Aversion in Children** by Mark Fishbein, MD, Sibyl Cox, RD SIU School of Medicine, Springfield, Illinois, Laura Walbert and Cheri Fraker CCC-SLP, CLC Preemietalk, Springfield, Illinois

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periods in the first year of life. Intervention also focuses on maintaining tolerance of taste and smell of food until swallowing skills improve to allow increased oral intake. Team members work together to provide multi-disciplinary oral sensory motor therapy programs. Preventative care is critical for pre-chaining care programs and is provided until the child is ready for a Food Chaining program.

Food Chaining© is a therapy program used to treat children with difficulty transitioning to more advanced textures of food or with moderate to extreme food selectivity. Food chaining is also only one part of a comprehensive treatment program. This is a technique that uses specifically selected foods or liquids as desensitization tools in treatment. Food chaining analyzes the relationship between food items and links items together by similar features creating a "chain." The feeding therapist and dietitian analyze the current food repertoire of the child (accepted, previously accepted and rejected foods) to determine patterns in taste/texture/temperature. The currently and consistently accepted foods/liquids comprise the core diet. Gradually, some of the preferred diet items are selected and modified slightly and/or linked to foods with similar characteristics. Flavor is modified prior to changes in texture. Food chaining also involves techniques of flavor mapping, flavor masking and use of transitional foods to make meals more acceptable to the child.

Chains can be written as part of a program to treat severe food selectivity, feeding aversion and dysphagia. The goal of a food chaining program is to expand the number and variety of accepted foods in the diet. New foods are introduced and rated with each exposure by the child or caregiver. Weekly food ratings determine which foods to modify next in the chain. The chance of refusal is reduced because food chaining is based on the child's preferences and therefore the child is not threatened or overloaded from a sensory standpoint.

## Tech Therapy

Another novel aspect of this treatment program is the use of modern technology. Videotaped feedings in the home environment are analyzed and used to provide a more in-depth analysis of the true nature of the feeding disorder. In order to determine the relative contribution of each of these impediments, feeding team members observe mealtimes at home (through videotaping) as well as in a clinic setting. Observers focus on parent/child interaction, pacing and duration of mealtime, feeding environment (including distractions, appropriate feeding utensils and set-up [seating, high-chair]), and child autonomy. Based upon this evaluation, members of a feeding team develop a treatment plan that helps the child reach his optimal feeding potential.

Outpatient treatment is often beneficial for children with long-term habits or significant medical or sensory-

based issues. Communication and contact with families may take place by direct service, or by telemedicine techniques with observation of "live" therapy sessions/meals in the home environment. Videotapes are submitted for re-evaluation and monitoring as well as communication with family and local/treating therapy team by phone, e-mail and voice mail.

## Research on Food Chaining

Food chaining was presented as a treatment method for severe food selectivity at the World Gastroenterology, Hepatology and Nutrition Conference in Paris, France in July of 2004.

A retrospective study was completed from September of 2001 until June of 2003 on ten subjects selected for food chaining programs. Range of diagnoses included cleft lip and palate, dysphagia, microgastria, cerebral palsy, BPD, autistic spectrum disorder, congenital heart disease and renal insufficiency. Chains were developed for the children based on their diet needs and swallow function. Eight of ten children had been in feeding therapy for over six months prior to starting a food chaining program. Six males and four females ranging from age 1-14 were studied. Accepted food items were analyzed at enrollment and again three months later and analyzed via paired t-test. Therapeutic sessions ranged from 0.5 to 2 hrs/week including voice mail, video-taped meals, phone contact with the therapist, telehealth and direct sessions. Food chaining led to an expanded diet in all cases ( $p < 0.05$ ) and there were no treatment failures.

## Conclusion

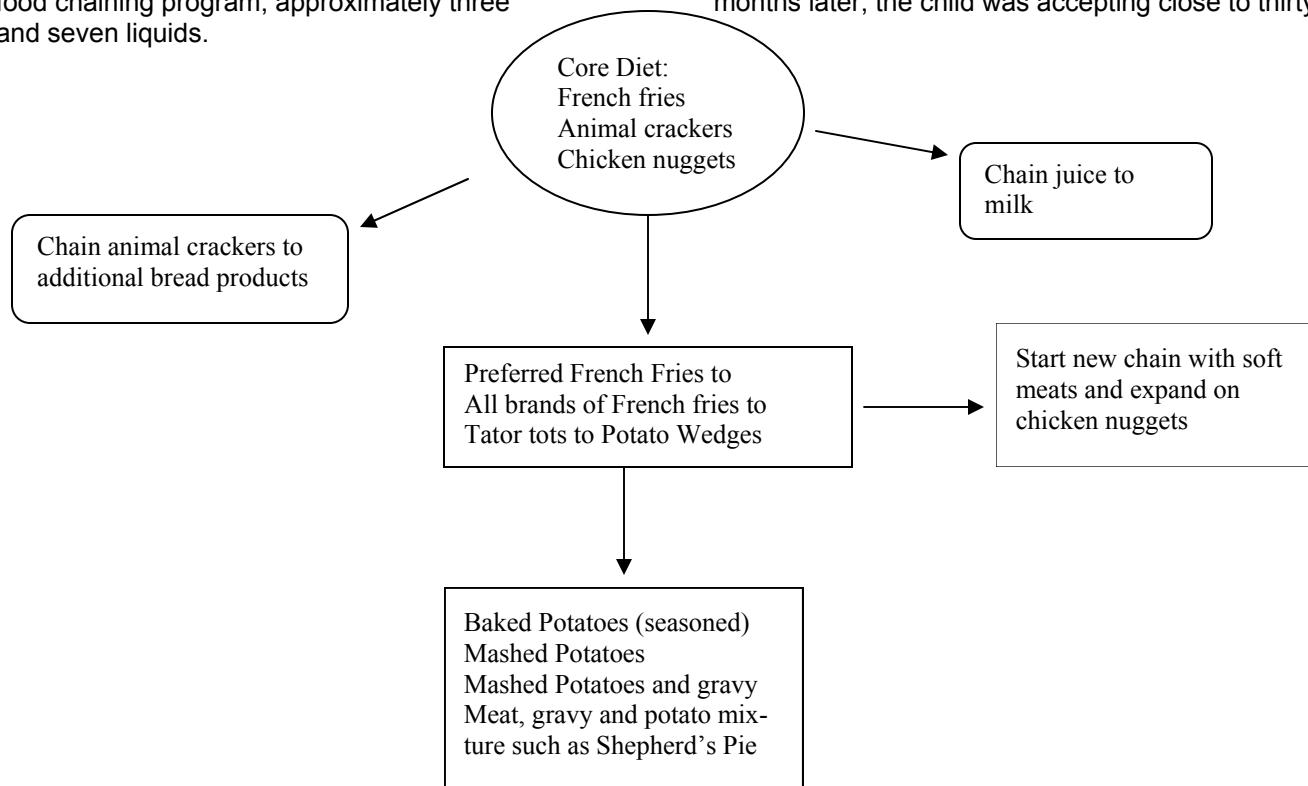
Pre-Chaining and Food Chaining Programs are effective multi-disciplinary methods of treatment of feeding aversion in children. Pre-chaining programs decrease the risk of developing feeding aversion. Food chaining programs expand the food repertoire and expose the child to a variety of tastes and textures of food. Gentle changes in food items are based on the child's response via the food chaining rating scale. Because changes are based on the child's preferences and reactions to change, risk of food refusal is significantly decreased. Food chaining programs are implemented in the child's home in the child's natural environment when appropriate. Nutritional status is improved with the introduction of foods from all food groups. The parent is empowered and encouraged by the child's progress in treatment, the child is guided through food rejection and accepts a wider variety of food across settings.



## Food Chaining Programs Continued from page 2

**Figure 1: Example of Food Chaining**

The following food chains were developed for a child with extreme food selectivity. Core diet consisted of three food items and one liquid. The three beginning chains were designed to expand the child's food repertoire and increase acceptance of various flavored and textured foods. Potato chain was introduced first and as the child was more accepting of change in the diet, the juice to milk and cracker chains were developed. Upon completion of the initial phase of the food chaining program, approximately three months later, the child was accepting close to thirty foods and seven liquids.



### Suggested Readings

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## **The Low Down on HI: The Challenges Underlying Oral Feeding Difficulties in Infants and Children with Hyperinsulinism.** by Staci Otto MS CCC-SLP, Children's Hospital of Philadelphia, Pennsylvania

Albeit rare (1 in 50,000 births), we're bound to have at least one infant or child with hyperinsulinism on our caseload. The children that get referred our way are some of the most challenging, frustrating and difficult feeders. We try every technique. We attempt to address every underlying issue, and they still won't eat... at least not much. To better understand the specific feeding issues surrounding hyperinsulinism, let's start by taking a quick overview of the disease.

### The Basics of HI:

We're sitting at our desks, reading the Pediatric Feeding Newsletter, and it's approaching lunchtime. We get out our lunch and eat. Our levels of glucose rise and in response our pancreas produces insulin. This Insulin secretion serves two main purposes in relation to our blood sugar levels. First, it helps to maintain normal glucose levels, which range from 70-100 mg/dL. Blood sugar levels below this normal range would be considered hypoglycemic and would cause us to feel nervous, sleepy, or dizzy, and in its severe form could cause seizures or coma. Levels of blood sugar above the range of normal would be hyperglycemic, similar to the difficulties encountered by diabetics (a topic for another article). Second, insulin helps with the storage of glycogen in our liver, allowing our bodies to access it through time. So back to our lunch... once we stop eating, our insulin secretion shuts off allowing stores of glycogen to be released to keep glucose normal even after we are through eating. This "switch off" of insulin allows access to protein and fat stores used as fuel- this way whether we are actively eating or not, our glucose remains in the normal range and our body has access to fuel.

Hyperinsulinism is a genetic disorder that causes excessive insulin ("hyper-insulin") secretion which results in low blood sugars ("hypo-glycemia"). It is the most common cause of persistent hypoglycemia in infants. Hyperinsulinism is classified into two forms: diffuse or focal. The diffuse form of the disease affects cells throughout the entire pancreas whereas the focal form is localized to one single region of the pancreas and is usually very small. The treatment for either type is essentially to try to normalize blood sugar levels, first pharmacologically and then surgically if necessary. Treatments include placement on IV fluids with sugar, followed by pharmacologic treatment with Diazoxide, Octreotide or Glucagon. Medically unresponsive HI requires a pancreatectomy, often up to 95-98% removal. For these kids, surgery is a cure for about 60% of focal cases and 40% of diffuse cases. Approximately 50% of patients post 98% pancreatectomy will still have low sugar levels and often still require dietary and/or pharmacological "control". Some children will develop diabetes mellitus following a pancreatectomy.

Brain damage can occur in up to 50% of children with hyperinsulinism if the condition is not recognized or therapy is ineffective. For parents, the consequences such as learning disability, stroke like cerebral palsy, blindness, seizures, brain damage or even death present a frightening diagnosis. Unfortunately, once families have had time to deal with and accept the diagnosis and any secondary disabilities, they are then faced with long term feeding challenges.

### Breakdowns of Oral Feeding...

Outside of apparent physical, anatomical or gastrointestinal dysfunctions, what goes wrong in the body of an infant or child with HI that causes poor feeding? Remember that feeding is a physiological process that depends on having the desire or appetite to eat as well as the ability to digest food. Our ability to digest food relies on a combination of sensory and motor functions as well as the cardio-respiratory, gastrointestinal, and metabolic components. And of course, our ability to process and digest food directly impacts our appetite and desire to want to eat.

At this point there are a few theories regarding where the breakdown towards oral feeding occurs- which can be grouped into two general issues: those of nature vs nurture. Are feeding difficulties inherent in the genetics of the diagnosis itself or are they imposed by the very efforts we have to take to manage hypoglycemia?

Researchers are now looking at the possibility that there could be a problem in gut motility due to the original defect that caused the HI. Problems with gut motility causing alterations in digestion, elimination, reflux and consequently appetite. Specifically, the diffuse form of hyperinsulinism is caused by genetic mutations of a specific channel in the pancreas called the KATP channel. These genetic mutations in the KATP channel have recently been identified in the gut as well, which leads scientists to question the actual impact of that defect on gut function. It is suspected that appetite regulation may be affected by pancreatic malfunction, however there is no research to support this as of yet. There is also new research demonstrating that the brain is sensitive to insulin whereas previously believed to not be the case, and scientists are looking specifically into how insulin signaling controls appetite regulation at a neurological level.

The very efforts we have to make to manage hyperinsulinism can themselves cause poor feeding. The need for utilizing IV fluids without oral feedings limit oral experiences and may hinder a child from learning how to feed during the first 2-3 months of life. The continuous presence of IV fluids can reduce feelings of hunger, resulting in limited acceptance. The need for long term tube feedings as well as regular "forced" tube feedings to regulate blood sugars result in limited oral experiences, decreased appetite, and often reflux. The presence of a nasogastric tube and the act of placing and replacing the tube has a negative impact on oral and pharyngeal sensation. The presence of a nasogastric or gastrostomy tube has also now changed the natural dynamics of our digestive system and can cause further alterations in normal gut motility. For children without a feeding tube there is additional stress on the caregiver to feed the child in order to keep sugars up, often resulting in forced oral feeds. This, as we know, can lead to oral aversion and strengthen behavioral refusals, not to mention the effect it has on caregiver-infant bonding during feeding time! Routine care of

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these children include pre and post feeding blood sugar readings, which involve heel sticks to withdraw blood. This means that children get a negative stimuli before and after each feeding and can develop association of pain with feeding.

The medications used to treat hyperinsulinism also have negative effects on appetite and gut function. Side effects of Diazoxide include fluid retention and decreased appetite. Octreotide can cause abdominal cramping from vasoconstriction, biliary sludging and also suppresses growth hormones (growth hormones stimulate the body to grow- if our body is not stimulated to grow, why would it be stimulated to eat?). Glucagon can cause nausea or vomiting (no need to explain that affect on appetite, right?).

Taking all of this into consideration can give us greater appreciation for the little oral feeding that these children do at all. But given that the treatments are necessary to avoid consequences like brain damage, what can we do to facilitate improved oral feeding?

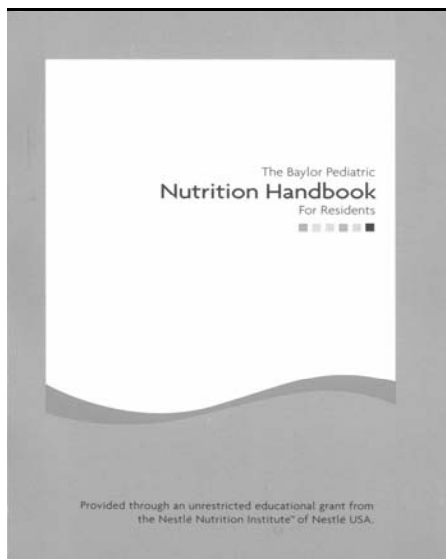
Unfortunately there is no definitive answer to this question. Researchers are just beginning to delve into many of these issues affecting feeding, and will hopefully open the door to new and exciting treatments. There are, however, a few things we can take into consideration:

- Begin oral feeding as soon as possible to allow for early oral and feeding experiences
- Offer pacifier or oral stimulation during tube feedings to allow for some positive oral input
- Focus on treating the hypoglycemia with medications rather than forced tube feeds when possible to allow for positive oral feeding opportunities
- Encourage the use of tube feedings when oral acceptance is limited to reduce the stress on caregivers and limit forced oral feedings

Get involved in feeding therapy early to facilitate positive feeding experiences

Most importantly, we can take our knowledge of this disease and the numerous diagnosis and treatment related oral feeding challenges and educate and share! By sharing these realities we can lower our frustrations, alter our expectations, and reduce stress, with the ultimate benefit being positive oral feeding experiences for these children.

(For references: email Staci Otto at [sotto601@yahoo.com](mailto:sotto601@yahoo.com))



### **RECOMMENDATION: THE BAYLOR PEDIATRIC NUTRITION HANDBOOK**

This pediatric nutrition handbook is authored by Baylor University and published through a grant from Nestle. It's a pocket size resource that includes information on growth/nutrition, feeding guidelines, and information on infant, enteral, and parenteral nutrition as well as information on the nutritional management of disease.

It contains calculations and charts for growth parameters as well as informative charts on infant, pediatric, adult and international formulas.

To get one of these reference books, it's free!  
Call Nestle at 1-800-628-baby, ask for your representative or ask for the book itself.





# THE POWER OF POOP

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Stooling is one of the bodily functions most overlooked. A regular stooling pattern is desired and yet our understanding of what represents a "deviation of normal" versus a pathologic pattern is not well determined. As a result, little anticipatory guidance is given to parents regarding stooling. Concern for constipation, however, is a very common problem in pediatrics. It is estimated that 3% of all visits to the pediatrician and 30% of visits to the GI are initiated for concerns of constipation. (4). A recent study identified the prevalence rate for constipation in the first year of life at 2.9%, and in the second year of life at 10.1% (9). Studies of older children reported rates up to 37% in children up to 12 years of age (13). Problems with constipation do not only involve frequency of stools and stooling effort; many behavioral, developmental and health consequences can also be associated with constipation, calling for increased awareness from health care providers.

The purpose of this article is to review what is already known about constipation and its influence on behavior and health. We would then like to suggest some anticipatory strategies and finally, discuss some interventions.

## *Normal Stooling*

Motility of the colon and transit time through the gut change with age. Gut transit time increases with age; it has been measured at 8.5 hours for infants 1-3 months and increases to 30-48 hours after puberty (3). In light of this, expected stooling frequency changes with age. However, there is wide variation in what is considered the normal frequency of bowel movements for specific age ranges. One author noted that for infants below the age of 3 months, 4 to 40 stools per week may be considered normal. Infants 6 to 12 months of age may have a frequency of 5 to 28 stools per week. For children ages 1-3 years, the range can be 4-21 stools per week. The expected stool for children over 3 years of age ranges from 3-14 bowel movements per week (6). Expected number of stools also differs depending on what the child is drinking. Breast fed children can stool with each feeding or less than once a day. Bottle fed children may have thicker stools that are harder to pass related to the differences in fats between formula and breast milk (5).

## *Constipation*

Just as there is great variability in range of normal stool frequency, there are many varied definitions of constipation. Some health care providers consider a decrease in stool frequency- with fewer than 3 stools/week- as a cause for concern. Other definitions include decreased stool frequency accompanied by harder consistency of stool with or without distress to the child (5). Another author defined constipation for infants and preschool children, as the presence of hard, pebble like stools for the majority of stools, or firm stools two times a week or less, with no evidence of structural, endocrine, or metabolic disease (5). Constipation was defined by a group of pediatric gastroenterologists from the North American Society of Gastroenterology and Nutrition (NASPHGAN) as a delay or difficulty in defecation, present for 2 or more weeks and sufficient to cause significant distress to the patient (8). Functional constipation, the most common cause of constipation was defined by an international group of pediatric gastroenterologists in infants and preschool children as at least 2 weeks of scybalous, pebble-like, hard stools for most stools, or firm stools 2 or fewer times per week, in the absence of structural, endocrine, or metabolic disease (9).

The most frequent precipitating factor for parents to seek help from a health care professional is the passage of a large, painful stool. Other factors that may contribute to the onset of constipation may include toilet training; a change in schedule or environment, for example starting daycare or all day school; traveling; introduction of solid foods; introduction of cow's milk; episodes of vomiting and/or dehydration; new medication; a change from breast milk to formula, or a change in formula; discontinuation of bottle feeding; or emotional stressor, such as parental separation or a family move (2,4,9).

Signs and symptoms of constipation will vary according to the age of the child. Infants may present with crying, grunting or straining before or during defecation, along with feeding difficulty. Toddlers often begin to withhold after the passage of a painful hard stool. They may rock back and forth, actively clench teeth or fists, or fidget in an effort to avoid defecating (5). Eventually, this withholding behavior may lead to impaction, and fecal soiling (8).

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Other behaviors that can be associated with constipation are decreased attention span, increased restlessness, frequent waking at night, irritability, and increased anxiety (3). Decrease in oral intake is also a frequent symptom of constipation. In fact, we have observed an average change of 15-20% of total volume of intake when a child is constipated.

### *Evaluation*

A detailed history is essential when evaluating constipation. Components of the history include present medications taken; age of onset including initial passage of meconium; frequency and consistency and size of stool; crying, bleeding, or other behaviors such as straining, red face, or squatting during passage of stool. Age of toilet training or any accompanying difficulties if applicable may be helpful. Episodes of daytime or nighttime fecal soiling should be ascertained. A dietary history should include changes in formula, appetite, and presence of feeding difficulties. Information as to amount of activity or exercise for older children may also be helpful. (5,11) In our clinic we have also found it helpful for parents when possible to come with a seven-day intake and stooling record. Parents are asked to record solid and liquid intake, with frequency, consistency, and accompanying behaviors during stooling.

Diagnosis of functional constipation most often is based on history and physical exam. A fecal mass may be palpated in the suprapubic area; other physical findings include a distended abdomen and hyperactive bowel sounds (5,8). In the absence of any red flag, which can point to an organic cause, no further testing is required. A radiograph may demonstrate fecal loading. Red flags to consider include age of onset less than 12 months of age; delayed passage of meconium; failure to thrive; no withholding, no soiling; empty recta or patulous anus; cutaneous-pigmentary abnormalities, urinary bladder disease. Initial diagnostic test may include thyroid function tests, fecal occult blood tests, lab tests to rule out Celiac Disease, serum electrolytes, calcium and lead levels (2,8).

### *Anticipatory strategies*

High-risk times in feeding development for onset of constipation are introduction of spoon feedings for children with severe volume limitation, introduction of table foods, introduction of cow's milk, and discontinuation of bottle feedings. The introduction of cow's milk has been frequently identified to result in episodes of constipation. Cow's milk has been reported to be the most constipating component of a toddler's diet (2). Commonly, the child appears to transition well from formula to milk, but then gradually if stools thicken and decrease in frequency, there is an accompanying decline in intake or difficulty transitioning to higher textures.

For a child with feeding issues, each visit should include information on stooling frequency, consistency and effort. That information should be compared to that child's previous normal patterns. If stools are slowing, dietary changes such as introduction of prunes, plums or papaya can be helpful in increasing stool output. Alternatively, Maalox or Mylanta in small amounts such as ½ teaspoon per day can be very helpful in softening the stool. Fiber (Benefiber, Maltsupex) can help some children by facilitating retention of water in the colon. However, for other children increased bulk in the stool may be more difficult to move through the colon aggravating the problem.

### *Treatment*

Treatment for functional constipation includes four components: parent education, disimpaction of the retained stool, maintenance therapy, and behavior modification. For a successful outcome, parents must first understand functional constipation, and encourage them to continue treatment to avoid relapse. Disimpaction of the hard stool may be achieved by hydrating the impacted stool with the use of enemas and oral agents. Once disimpaction is achieved, maintenance therapy is initiated. This is achieved with the use of oral agents stool softeners such as Maalox, or Mineral oil. Oral osmotic agents can include Milk of Magnesia, Miralax, and Lactulose. Miralax and Lactulose may help to improve transit time through the colon (7). Those products containing Senna are recommended for only short-term use. Bulk forming laxatives such as Metamucil work by adding bulk and water to the stool, allowing the stool to pass more easily (3). Doses for oral agents may need to be adjusted depending upon effectiveness and tolerance. It is challenging to offer these agents to young children due to taste, and parents

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are often more successful when they place these in the child's milk or juice. Dietary changes may be suggested including the introduction or increase of fiber-rich foods such as fruits, vegetables, and whole grains (11,12). These changes may be more successful to implement when the child is feeling better. In our clinic, we have noted a dramatic improvement in intake once the constipation was treated.

The final step is behavior modification. Parents are counseled to include routine toilet sitting for 5 minutes 2-3 times a day, and offer praise and rewards for compliant behavior. Maintenance therapy is discontinued only after consistent regular bowel movements are achieved, and may continue for many months. Tolerance and addiction to these agents has not been noted for the majority of patients (10). However, relapse is common, and close follow up is recommended (6,11).

In conclusion, although constipation is considered a common pediatric disorder, parents may have difficulty initially identifying a problem. Children may demonstrate constipation and accompanying discomfort in a number of different ways. Once the diagnosis of functional constipation has been diagnosed, key components to treatment includes parent education and persistence with maintenance therapy. Regular follow up and continued support are essential components to therapy. Signs of improvement may include an increase in intake with the successful treatment of constipation.

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### *On the Research Front:*

**Chitkara DK, Camilleri M, Zinsmeister AR, Burton D, El-Youssef M, Freese D, Walker L, Stephens D. Gastric sensory and motor dysfunction in adolescents with functional dyspepsia. J Pediatr. 2005 Apr;146(4):500-5.**

Validated, noninvasive studies were used to compare sensation and motor function of the upper gastrointestinal tract in adolescents with functional dyspepsia (FD) and in control subjects. Results indicated that adolescents with FD demonstrate increased postprandial symptoms after challenge, delayed gastric emptying, and a reduced gastric volume response to feeding.



# Case by Case: Simulating an intensive feeding program at home

by Krisi Brackett MS SLP/CCC

Mimi is a 3 year old female with autism that I evaluated in April. She has been dependent on a g-tube for all nutrition since infancy. In 6 weeks she was eating all of her nutrition orally. I attribute her remarkable success to the fact that ALL the pieces were in place for a successful outcome.

When I met Mimi she was receiving pureed food through her g-tube (8 oz of pureed foods and 4 oz of milk 5X/day) with what appeared to be good tolerance. She had also just begun oral feeding attempts 5X/day. Pureed foods or solids such as cheerios were offered via spoon plus milk in a sippy cup. Acceptance was inconsistent and limited. She protested by using poor mouth opening, covering her mouth, or trying to get up. She did not chew.

## What pieces were in place that led to her successful transition off the tube so quickly?

1. **Great GI management:** Mimi has a long complicated GI history that includes frequent and projectile vomiting the first 2 years of life, NG tube at 4 months for poor weight gain, multiple formula trials, j-tube with vomiting, manometry evaluation with diagnosis of duodenal block at 2. Meds include prevacid, amytrip-toline, and mirilax. Medical management and time decreased gut sensitivity and tolerance eliminating retching and vomiting.
2. **Her Family:** Mimi's parents were determined to get to successful feeding. They sought out professionals to assist them, were savvy about what they felt was helping Mimi and continued to expose her to oral feeding attempts on a daily basis.
3. **ABA therapy:** Mimi receives ABA (applied behavioral analysis) intervention 40 hours per week. Trained therapists work with Mimi on skill development daily using behavioral retraining techniques with success.

**The Feeding Plan:** First, I encouraged Mimi's parents to keep her on all of her GI meds to maintain gut comfort and to especially continue her stooling regime of 1-2 stools per day. Then a behavioral feeding plan was initiated with the help of her ABA therapists. They agreed to add the feeding plan into their daily routine with Mimi 4-5X/day. We started by eliminating the oral feedings the family was doing. They were reinforcing negative behaviors. We backed up to offering a dry spoon with good mouth opening for a reward (20-30 seconds of play). Initially, Mimi responded beautifully and all of her aversive behaviors disappeared. We then moved to a dip spoon (dip in puree), she began wiping her mouth, turning away from the spoon, grimacing and wanting down. We backed up to dry spoon to regain our momentum and intermittently dipped in water and juice. Acceptance of the dip in juice was slow. A meeting with the ABA therapists to brainstorm resulted in some ideas. They recommended giving Mimi intermittent familiar commands to follow (touch your nose, point to a picture,) interspersed with her eating commands ("open" for the spoon). The technique worked and improved her success and acceptance. We also limited the length of the session to 10 minutes with an external cue to signal the end. Over the next 2 weeks, something clicked with Mimi. Her acceptance improved, the ABA commands were phased out. In 2 weeks she progressed to puree going from 30 bites to 5 ounces, to 8-9 ounces. She opens well and clears the spoon. Feedings take about 10-15 minutes. Her mom told me that it was actually fun to feed her. (note parents are giving 8 oz. of free water at night for hydration needs).

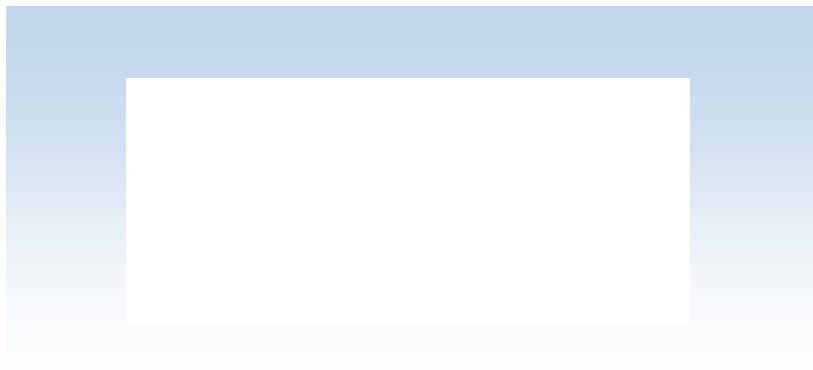
**Future:** At this point, we are working toward chewing and adequate hydration. We have added cup sips and lateral placement of puree to encourage lateral tongue movement to the daily feedings. The ABA therapists are working on lateral biting on a chewy tube and biting on dry solids to the non-feeding daily therapy.

\*\*\*I believe Mimi has been so successful because of the GI management she had in combination with the intensive feeding plan her family was able to implement in her home. Doing 4-5 oral feedings/day plus g-tube feedings is not feasible for most families. I feel that with the help of her ABA team we were able to simulate an intensive feeding program in the home.

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### On the Research Front:

**Smith AM, Roux S, Naidoo NT, Venter DJ. Food choice of tactile defensive children. Nutrition. 2005 Jan;21(1):14-9.**

This study confirmed that the eating habits and food choices of tactilely defensive (TD) and non-tactilely defensive children differ significantly. Based on parental questionnaire, children with TD had a fair to poor appetite. They hesitated to eat unfamiliar foods, did not eat at other people's houses, and refused certain foods because of the smell and temperature. They also had a problem eating vegetables. They often gagged and/or bit their inner lips and cheeks. The results showed a definite difference in the limited selection of foods that TD children chose and a pronounced aversion toward textures or consistencies, smells, and temperatures of food as compared with integrated children.

**Berger-Gross P, Coletti DJ, Hirschhorn K, Terranova E, Simpser EF. The effectiveness of risperidone in the treatment of three children with feeding disorders. J Child Adolesc Psychopharmacol. 2004 Winter;14(4):621-7.** This case series describes the treatment of 3 consecutive preadolescent children admitted to our rehabilitation facility with severe feeding disorder and histories of failure-to-thrive (FTT) that had required enteral nutritional interventions. Each child also had comorbid anxiety and mood symptoms. The addition of risperidone to behavioral and psychopharmacologic treatments was observed to significantly increase oral intake and accelerate weight gain. In 2 of 3 patients, assistive feeding interventions were successfully discontinued; and in a 3rd patient, enteral nutritional support was reduced by 74%. These cases suggest that risperidone may be a safe and effective adjunctive treatment, when behavioral feeding therapy is not sufficiently successful for children who have chronic and complicated medical and psychiatric presentations.