



Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders,

This issue is packed with new information to assist you with your evaluation and treatment. An important correction from the last issue: Some of you have contacted me about having difficulty getting a copy of Nestle's Baylor Nutrition Handbook. To get a copy of the Baylor Handbook, call Nestle rep Marina Marcroft at 1-800-633-2330, ext 8236. Give her your name, address, phone, and that you are interested in receiving a copy of the Baylor Handbook. Thanks, Krisi Brackett MS SLP/CCC

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Fun With Food -Program to address food aversions and eating challenges by Tania Stegen-Hanson, OTR/L

During the past three years, the staff at Achievement Therapy Center have researched, undergone training and presented successful individual as well as group treatment to address the needs of the resistant eater.

Who are Resistant Eaters?

Resistant Eaters often exhibit one or more of the following:

1. Limited food selection. Total of 20 foods or less.
2. Limited food groups. Refuses one or more food groups.
3. Anxiety and/or tantrums when presented with new foods. Gag or become ill when presented with new foods.
4. Experiencing food jags. Requires one or more foods be present at every meal prepared in the same manner.
5. Diagnosed with a developmental delay such as Autism, Aspergers Syndrome or Pervasive Developmental Disorders-Not Otherwise Specified.

Each child who experiences problems with eating is unique and therefore requires an individualized plan to meet his or her needs. A comprehensive treatment plan includes a multilevel and multisensory approach that requires a commitment from parents and the professionals working with the resistant eater. For school-age children, it is important that the school team creates opportunities to implement the plan during the school day. At Achievement Therapy Center, a thorough review of the child's medical history and assessment of oral-motor delays are done before beginning a treatment program.

Although each child is different and the goals for the treatment plan must reflect the unique characteristics of the child, there are some general

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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goals for all treatment plans. These include:

- To create a safe, positive, and nurturing meal-time environment.
- To expand the child's responsibility in preparing, consuming, and cleaning up at mealtimes.
- To improve the child's oral-motor development.
- To address all physical needs of the child during eating (including gastro-intestinal comfort, sitting position and comfort, postural support, ability to manage eating utensils)
- To provide multisensory exposure to new foods.
- To respect the child's communication and response to eating.
- To expand the child's repertoire of foods and create a balanced diet.

It is important to remember, the plan is not intended to be an adverse or punitive program that forces or bribes the child to eat. Throughout, the focus is on exploration and learning about new foods and eating.

Designing and implementing a treatment plan for resistant eaters is not a one-size-fits-all approach.

One of our many success stories to share is about a charming boy who's name is Logan.

Logan is going on four years old. He started attending individual occupational therapy sessions 1 ½ -years ago. Logan was diagnosed with failure to thrive, he lived on rice milk and Pediasure and mouthed a few foods before spitting it out. Mealtimes generally turned into a power struggle resulting in meltdowns at the table and long violent tantrums.

The results of Logan's initial oral motor assessment indicated weakness in his tongue, lip and jaw strength. Logan did not know how to motor plan with his tongue to move food between his teeth to chew and then to safely swallow.

During clinical observations it was noted that Logan demonstrated general weakness in his

body, especially the muscles in his back and stomach which support his trunk, posture and respiration. Logan also demonstrated signs of gastro-intestinal discomfort. He threw up after eating, hiccups and wet burps were frequent and bowel movements were inconsistent.

Together with Logan's parents, a treatment plan was developed.

It is important to remember that a treatment plan should focus on three primary areas:

Part 1: Environmental Controls

Part 2: Physical and Oral-Motor Development

Part 3: Stages of Sensory Development for Eating

Each area of the plan may be addressed individually or all may be implemented simultaneously. It is important for all involved to take the time to write out a detailed plan that can easily be implemented. The plan is not intended to include rigid and inflexible deadlines. The focus should be on learning new skills and exploration without the insistence of meeting an arbitrary timeline.

As Logan became more willing to engage in the activities provided during his therapy sessions, signs of sensory integration dysfunction became more evident. He craved large amounts of spinning, swinging and deep pressure sensations such as squeezing his body into tight spaces for example between pillows or purposefully crashing into objects and people. He also demonstrated defensive reactions to tactile input. Even holding a koosh ball during a target throwing game caused a gag reflex.

Logan was therefore provided with a sensory diet involving activities to address his need for vestibular (movement) and proprioceptive (deep pressure) input, at the same time desensitizing his tactile (touch) system to be able to tolerate touching and handling messy substances and in order that he is better able to explore his environment.

The family was asked to follow through with an individualized sensory diet and specific

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home program activities/exercises and together with weekly occupational therapy sessions, the treatment plan included addressing Logan's oral motor skills, gastro-intestinal comfort, respiration, postural strength, motor planning skills using various neuro-developmental and sensory integration techniques.

As Logan progressed, he went through food jags in which he would only eat orange stage two baby foods. Researchers have reported that it may take up to 10 - 15 exposures of a new food before a resistant eater is ready to move on to the next sensory stage of development. Therefore, a comprehensive treatment plan should include multiple opportunities for exposure at each sensory level.

Despite the emotional turmoil his parents were experiencing, they followed through consistently exposing Logan to a variety of foods during mealtimes and during scheduled play times. A breakthrough happened when Logan started attending a Pre-K program with supportive teaching staff who were willing to follow through with the same strategies during snacks and meals at school.

Logan's parents were dedicated in following through with home programs, behavior management strategies and consistent therapy attendance. This December he will be discharged from weekly therapy services. His mother reports that Logan is now eating textured, solid foods from all the food groups and in fact, he has a better appetite than his older sister!

Logan's food aversions were not able to disappear overnight. Although it has been a slow process, requiring a consistent, nurturing, skilled approach across all environments (home, school and therapy), it has certainly been a very rewarding process.

For the reader who is eager to implement a plan, here are some guidelines and strategies for structuring the environment:

1. Design a consistent schedule that includes all meals and snacks. The schedule should be posted and a timer used to assist the child. Children who struggle with eating a balanced diet should only eat meals and snacks according to the schedule.
2. Select an appropriate setting with minimal distractions. The kitchen table is the most appropriate setting for a meal. Some modifications may be necessary depending on the child's age and size. Children should eat all meals and snacks at the designated setting.
3. Create a supportive climate with written age-appropriate rules. A supportive environment respects the child and does not allow adults to invade the child's mouth without permission. Never discuss the child's eating habits or how much he eats during the meal. If inappropriate behavior is exhibited during the meal, remove the child from the table letting him know that his behavior is sending a message that lets you know he is not hungry. The family should finish the meal and the child may receive a snack according to the schedule.
4. Select child-friendly foods and portion sizes. Select one menu for the entire family. A family meal should include a protein or meat, starch, fruit, and/or vegetable, and milk. When planning a family menu, consider selecting child-friendly foods. Always provide the resistant eater with at least one serving size of a preferred food item. Consider using a smaller plate to encourage child size servings. A smaller portion allows the child to see the results when taking a few small bites.
5. Address food jags. A food jag refers to the insistence on the same food, or the same utensils, or even the same setting over long periods of time. Do not cater to the child's rigidity in wanting the same foods. Make slight changes in the presentation of the food or change the brand names. Provide the child with forced choices for food items and/or utensils. Be sure the changes are small and do not create anxiety for the child.

Fun With Food ~Program to address food aversions and eating challenges by Tania Stegen-Hanson, OTR/L

Children naturally learn to eat new foods through the developmental sensory stages of tolerance, touch, smell, taste, and eating. Further information on the **Stages of Sensory Development for Eating** and activity suggestions for implementing a treatment plan, are discussed in detail in the book: **“Just Take A Bite”** by Dr. Lori Ernsperger and Tania Stegen-Hanson. For more information on occupational therapy intervention and Fun With Food Camps, contact Tania at Achievement Therapy Center, telephone # 220-5514, or email address: achievementtc@aol.com.

Question & Answer:

Fessler DM, Abrams ET. Infant mouthing behavior: the immunocalibration hypothesis. Med Hypotheses. 2004;63(6):925-32.

Avid mouthing, (infant behavior of sucking objects), is a pattern characteristic of the first 2-3 years of life, with its most intensive manifestation occurring during the first year. Although traditional accounts explain infant mouthing as a source of sensual gratification and/or environmental exploration, these proximate hypotheses are inconsistent with the high costs of mouthing, including choking, poisoning, and exposure to pathogens. The authors propose that mouthing serves to proactively expose the naive gastrointestinal tract to environmental antigens and commensal bacteria while under the sheltering umbrella of breastfeeding. Mouthing functions to accurately calibrate the developing immune system, including antibody production and mucosal immunity, to the local disease ecology. The critical exposure period is not open-ended, as failure to expose the gut to an adequate number of antigens early in life is associated with an increased risk of allergies, asthma, and atopy. Weaning initiates a number of immune changes that may program the neonatal immune system into certain life-long responses.

Dr. Fessler answered a few of my questions based on his interesting research:

1. What gave you the idea to form your hypothesis initially? As a speech/feeding therapist, we are taught that mouthing is for exploration and comfort.

First, it is important to distinguish proximate explanations from ultimate ones. The 'comfort' idea (which is very common) is a proximate explanation -- it is like saying people have sex because it feels good. Proximate explanations do not solve ultimate questions -- noting that babies like to mouth stuff, and that it calms them down (which is really more of a description than an explanation, frankly) does not explain why babies' brains are designed in such a way that mouthing behavior is rewarding. There are at least three possibilities, namely a) this is an accidental consequence of something else (e.g., babies brains are built so that nursing, an important behavior, is rewarding, and mouthing is just an accidental side-effect of a nursing motivation system); b) this is a hold-over from some previously adaptive behavior (and hence is on the way out, evolutionarily, much as human wisdom teeth are disappearing); or c) this is a functional behavior (i.e., it enhances the in-

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Question and Answer:

dividual's biological fitness, or at least would have done so in ancestral environments). The 'exploration' hypothesis (also very common) is an ultimate explanation -- it claims that babies mouth in order to gather information. The problem with this explanation, and the thing that really bothered me for years, is that babies have hands and eyes just like older children and adults, so it is unclear why they should use a completely different sensory modality to gather information about the world. Moreover, given that mouthing is potentially very costly (choking, infection, etc.), and given that infants and young children are particularly vulnerable to these costs, the exploration hypothesis is simply implausible. As cited in the paper, there is experimental evidence indicating that exploration can only account for a fraction of mouthing behavior.

2. I'm fascinated by your ideas because a high percentage of children that we treat for poor eating (this might include food refusal, failure to thrive, etc) have histories significant for not mouthing anything at all. In fact many parents report that they never put anything in their mouths. There is a high correlation between the failure to thrive population and kids with eating problems and gut issues. I'm wondering if their lack of mouthing helped lead to gut issues which then led to GI issues and food refusal.

Interesting idea. I'm not a clinician, so I'm somewhat hesitant to make clinical statements, but it is at least plausible to suggest that failure to gain adequate exposure to locally-prevalent pathogens during development results in improper GI development of a sort which would subsequently create a variety of feeding problems.

3. Do you have any ideas on why a child would not mouth in infancy? I have always guessed that many of these infants have existing gut issues and are hypersensitive in the oral area therefore avoiding mouthing.

Possible. Alternately, there might be some more immediate problem (hypersensitivity in the oral cavity due to wounds, infection, tooth eruption, etc.) which decreases mouthing, leading to improper gut maturation, which might then feed back on mouthing behavior. But I'm really speculating here, I don't have any facts or data that speak to this question.

4. Since the mouthing hypothesis is tied in with breast feeding, what does it mean for formula fed infants?

If our hypothesis is right, then the best thing for kids is a combination of a not-obsessively-clean environment (e.g., household pets are present, antibacterial soaps are not used, etc.) and extensive breastfeeding; if we are correct, then disrupting either part of this equation will likely cause problems -- kids who live in a too-clean world develop atopic disorders and similar immune misfires, while kids who mouth plenty of grubby stuff but are not breastfed are more likely to get sick due to pathogen ingestion (note that the costs of such illness might not be limited to the disease phase itself, as it is at least possible that the sheltered exposure generated by mouthing + breastfeeding is necessary for proper GI maturation and immune maturation, hence even if the kid can fight off the infection on his or her own, the developmental benefits of pathogen exposure may still be missing -- but again, I'm speculating here).

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Question and Answer:

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5. An interesting study, would be to follow kids who don't mouth for a few years and look at their GI development. Any thoughts?

Yes, I would love it if someone would do this. We've thought about comparing immune functioning in similar populations that differ with regard to mouthing opportunities (for example, it is likely that very little mouthing occurs in cultures in which infants are swaddled). I think there are many interesting avenues open for investigation.



We asked a variety of Feeding Experts to give us advice, a favorite tool, recommendation or a few words of wisdom.....

Polly Tarbell SLP/CCC, The Encouragement Feeding Program, Kluge Children's Hospital, UVA, Charlottesville, VA:

No particular therapy tool or technique but the most important aspects of our program and my philosophy include:

- 1) Looking at the whole child—not just the mouth
- 2) Individualizing to the level that the child is accepting
- 3) Timing of intensive service provision
- 4) Helping the child develop a Positive relationship with food

Cis Manno SLP/CCC, Private practice, PA:

This is a hard question!! I think that a favorite thing is to be able to have The availability of someone (an expert) to ask questions either by email/phone/etc.

Debra Beckman SLP/CCC, Private Practice, FL:

The clients love using the Lip Sync Cards from Educational Insights (www.educationalinsights.com) also available from Super Duper. Each card has a graphic, a picture and a sticker that shows the mouth moving to make that sound. Great for imitation and for apraxia. Also, the EZ spoon and EZ spoon soft for tube to oral transition, available from ARK Therapeutic Products, pdp products, and other sources.

Catherine Shaker SLP/CCC:

Pacing -- it's the most critical intervention one can utilize with preterm infants

Krisi Brackett SLP/CCC, Salt Lake city, UT:

Don't underestimate the influence of the gut on oral food acceptance. And remember the importance of practice to develop oral motor skills.

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The Ketogenic Diet-A "Magic" Diet?

By Sharon Wallace, RD

The ketogenic diet is a special diet used to treat seizures. The basis of the diet is using a high fat, moderate protein and very low carbohydrate diet to induce ketosis (an excess of chemicals called ketones in the blood, produced when the body uses fat as its main source of energy). The ketosis is thought to be the mechanism that controls the seizures, although the exact way the diet really works is not known. The goal of this diet is to achieve seizure control without the use of anticonvulsant medications, as so many of them have negligible effects on children's behavior and degree of consciousness.

Certain types of seizures tend to respond better to the diet than others. Children with Lennox-Gastaut syndrome, myoclonic, atonic and absence seizures generally have better results with the diet than those with petit-mal and psycho-motor seizures and other types of epilepsy. Children tend to respond to the diet better than adults; again, researchers are not sure why this is the case.

The ketogenic diet has gained much more attention in the last 10 years, but references to fasting in order to control seizures have actually existed since Biblical and Medieval times. It was used frequently until the advent of many of the anticonvulsant drugs, and then it lost popularity in exchange for the use of medications. The interest in the diet was initiated again in the 1990's when a child was prescribed the diet and had an excellent response to the diet. This gained widespread attention from the media, and has been becoming more of a mainstream treatment for seizures ever since.

It is usually considered if a child does not respond to 2-3 seizure medications prescribed. Every child will react differently to the diet, and some will continue to have seizures despite precisely following the diet. Studies have shown that about one-third of children who try the ketogenic diet will become almost seizure free, one-third will have a reduction in the number of seizures and the other third will not respond to the diet.

Calories are restricted to about 75% of the typically recommended amount for one's age, a mild fluid restriction is calculated, and a child must supplement their diet with calcium and multivitamins (these must be sugar-free, or can actually take the child out of a ketotic state and the diet will not work.). While a child is not "starving" the combination of fewer calories, less fluid and a high-fat diet mimics starvation in the body and produces these ketone bodies, which in turn are thought to control the seizures.

Ketone bodies can be measured in the urine by using paper strips, similar to what one would use when measuring ketones in diabetes. As the child continues on the diet, medications are carefully tapered, and parents and the medical team watch for signs of "breakthrough" seizures. It can typically take up to three months for a child to be on the diet before the efficacy can be seen-in this time period, it is not unusual for the dietitian to have to make many adjustments in the diet calculations to "fine-tune" it perfectly for each child.

Typical foods a child may consume as the main part of their diet are whipping cream, butter, mayonnaise and peanut butter. It can be a very challenging diet to follow, as the foods are fairly restricted, large amounts of fat are used, and children cannot usually have typical special treats like birthday cake and other sweets or convenience food that kids so often like to eat, so families need to get creative. Even minor amounts of carbohydrate from medications (or even sunscreen!) can cause breakthrough seizures. It is very important to note that it is

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The Ketogenic Diet-A "Magic" Diet?

By Sharon Wallace, RD

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considered a "medical-nutrition therapy" and should never be started by the family without medical and nutritional supervision.

When the decision to begin the diet is made, a child is typically admitted to the hospital to undergo a fasting period to induce the ketosis. A close watch on the child's lab work and blood sugar levels is monitor side effects such as low-blood sugar, constipation and kidney stones can result from the diet, and need to be monitored closely. Families learn how to properly measure foods and work very closely with the dietitian so that they are comfortable managing the diet at home.

A typical day of meals may include a breakfast of an egg and mushroom omelet made with a lot of butter, whipping cream to drink and applesauce, lunch could be hot dog wrapped in a lettuce leaf with mayonnaise and a small amount of ketchup, potato chips, and diet orange soda mixed with whipping cream, and for dinner, chicken, green beans with a mix of butter and mayonnaise, and whipping cream to drink. As one could imagine, this can be a difficult task for both parents to prepare and present to a child, and some children refuse some foods-this can alter ketosis, which places more pressure on the parents to be sure the child eats everything.

Despite the risks, the rigidity of the diet and the mixed individual success, I have not had any patients who have regretted at least trying this diet as an option for their child. As the diet draws more attention, more studies are being conducted that look at growth, long-term affects on lab values such as cholesterol and triglyceride levels, and there is currently some research underway that is looking at the use of the popular Atkins diet as an alternative option to the traditional ketogenic diet.

For references contact Sharon Wallace at sharonwallace@nc.rr.com

Advice from Feeding Experts...

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Maureen Lefton-Greif SLP/CCC, Johns Hopkins Medical Center:

I don't have a favorite tool or technique. As far as advice, I will take the liberty of quoting a former professor of mine, Dr. James Nation, who emphasized that one must have a strong "fund of knowledge". In addition, one must possess the skills to evaluate each new tool and technique to determine whether there is sufficient evidence to justify using it.



**MaryLouise E. Kerwin, Ph.D., BCBA, Associate Professor
Department of Psychology, Rowan University:**

My advice is to collect objective data and review it frequently as a method of assessing treatment progress or failure.

Case by Case: Constipation = poor intake by Krisi Brackett MS SLP/CC

TI is a 1 ½ year old male seen for feeding intervention because of concern over a severely limited diet and poor food acceptance.

Medical Diagnoses: bilateral hearing loss, failure to thrive, s/p rsv X 2 (5 months, 18 months), s/p rotovirus (14 months), inguinal hernia diagnosed.

Medical History:

Birth History: TI was the 6 lb, 10 oz. product of a full term gestation without complications.

ENT/ Pulmonary History: severe hearing loss, multiple ear infections (tubes placed), frequent illnesses and that he has had 8-9 colds with “puss pockets” in his throat and drainage.

GI History: TI was a colicky baby. Gags with textures and retches 1-3X/week, frequent bad breath, and difficulty sleeping (crying and coughing). Severely restricted diet and liquid intake. By report, some vomiting last month which may have been related to his Pediasure. It was stopped and vomiting improved. He has also had bouts of rashes and diarrhea. RAST testing was negative. He receives mirilax occasionally (difficulty administering it with the volume of liquid required). He has a BM every 2 days that is firm. His anal area is red by report. He also had c-diff and was treated with flagel.

Development History: TI is followed by EI for hearing and feeding. WML motorically.

Nutrition/ Growth history: TI has been seen at a nutrition clinic where they recommended power packing calories and periaquant (with no change). By report, TI began falling off the growth curve around 9 months. He has gained 1 ½ pounds in the last year. All testing has been negative. Current weight: 20 lbs. (3rd %ile): Current height: 32 inches (20th %ile)

Feeding History: TI nursed for 8 weeks and seemed constantly hungry. He cried frequently and was colicky and cranky. Mom reported that she offered him a bottle at 8 weeks and that he drank 18 ounces of Lipel in one sitting. She continued feeding him Lipel and he became constipated. He started mirilax at 3 months for constipation. At 6 months, he was offered baby food but didn't like it. By 8 months, TI was taking about 2 jars of puree per day plus bottles. He has never been a good eater per mom. At 8-9 months, he started table foods. By report, he stopped all foods by 9 months. When asked, Parents could not think of a reason for the stopping of foods except that he was having ear infections. His bottle was stopped at around 20 months because parents were worried about his teeth and that his food intake decreases when he has a bottle.

History

Current Feeding: Limited diet. He may eat a small bowl of oatmeal in the morning with cream and sugar. Lunch and dinner may be licking cream cheese, a half a yogurt, ½ chicken nugget and approximately 8 ounces of milk per day.

Oral-Motor Exam: Based on observation: normal for structure and function.

Observation of eating: He self fed cream of potato soup. He ate a bowl and half demonstrating self feeding ability and good bolus control and transfer. He was able to chew the chunks with lateral chewing and lateral tongue movement. There were no indications of swallowing difficulty. Parents reported that he had not eaten since breakfast and I observed him at 5:30 pm.

Exam

Assessment: TI is a 1 ½ year old male with a severely restricted diet both liquids and food who presents with a severe feeding disorder characterized by: **Oral-motor:** Normal oral structures but mildly immature oral motor pattern (emerging rotary chew with occasional use of midline tongue or suck pattern), **Gastrointestinal Issues:** soft signs of GER and motility problems (volume limiting, extreme food refusal and pickiness, poor intake, retching 1-3 times/week), frequent ear infections, bad breath, colicky as an infant, and gagging on new foods, constipation, **Nutrition:** Poor intake and poor weight gain. Currently less than the 3rd%ile for weight for height, **Behavior:** food refusal, food selectivity, and demonstrates aversive feeding behaviors.

Assessment

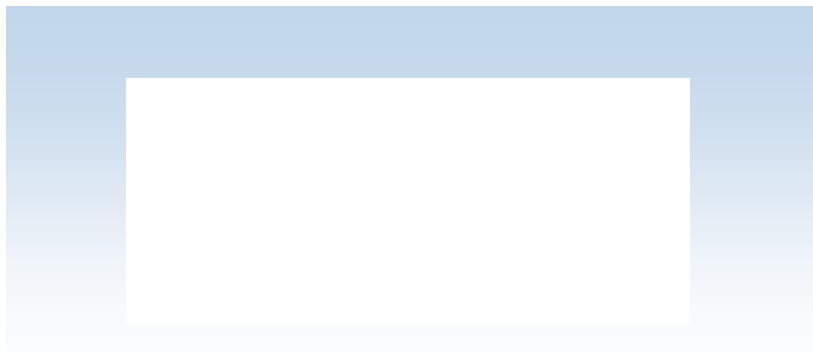
Intervention: In conjunction with the GI doctor, intervention consisted of improved stooling (mirilax and benefiber), an endoscopy revealed mild esophagitis and prevacid was prescribed. It is noted that it took several weeks to improve stooling pattern. A behavioral feeding program was implemented using pureed texture to improve intake and appropriate calorie goals were made. Intake improved with the behavioral program and as stooling became easier he began to want to eat. In 4 months, TI was stooling, happier and eating age appropriate foods and volumes independently.

Intervention

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Hiro Publishing
3106 Lincoln Street
Salt Lake City, UT 84106
www.feedingnews.com
phone: 801-599-8250
Email: feedingnews@earthlink.net

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On the Research Front:

Patel, M. R., Piazza, C.C., Layer, S.A., Coleman, R., & Swartzwelder, D. M. (2005). A systematic approach of food textures to decrease packing and increase oral intake in children with pediatric feeding disorders. *Journal of Applied Behavioral Analysis*. 38, 89-100.

This study examined food packing and subsequent FTT/poor intake in 3 children. Caloric intake increased with lower textured foods (less packing). Textures were increased over time with good results. A good article to read about packing as an avoidance behavior.

Mason, S.J., Harris, G., & Blissett, J. (2005). Tube Feeding in Infancy: Implications for the development of normal eating skills. *Dysphagia*. 20, 46-61.

A nice review of the literature of tube feeding and its effects on normal eating and drinking skills. Factors are identified that may contribute to later feeding difficulties such as age at which oral feeds begin, medical complications, exposure to taste and textures during sensitive periods, aversive experiences and different methods of delivering tube feedings.

Buyukgebiz, B., Bekem, O., Ozturk, Y., Aydin, A, Tasci, C., Arslan, N., & Durak, H. (2005). Delayed gastric emptying in children with poor appetite. *Acta Gastroenterol Belg*. Apr-Jun;68(2):230-2.

Anthropometrical measurements, daily energy intakes and gastric emptying times were determined in 36 children with poor appetite. Results indicated that malnutrition was found in 63.9% and gastric emptying was delayed in 58.3% of all cases. Children with delayed gastric emptying were significantly older and malnutrition was significantly higher in this group. In children with poor appetite, probability of gastric motility disorders should be taken into consideration. Especially in children with failure to thrive at preschool and early school years gastric motility studies should be undertaken.