



Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders:

Welcome to the first issue of our 10th year! In this issue we have 3 contributing articles. The first article is from the intensive feeding team at Helen DeVos Children's hospital, in Grand Rapids, MI on using an intensive feeding team approach. We continue our chapter excerpt with part 2 from the new book by Elizabeth Strickland, RD, LD titled Eating for Autism ... The 10 - Step Nutrition Plan to Help Treat Autism, Asperger's, or ADHD, and we have an interesting case study on tube weaning in infants from a hospital in Israel.

Just FYI, I have received several requests for an article on getting better referrals, so look for that in the next issue, due out in June.

Thanks and enjoy,
Krisi Brackett MS CCC/SLP
feedingnewsletter@gmail.com



Editorial:

Taking a team Approach..

Our 3 contributing articles all have one common thread- a team approach to pediatric feeding disorders.

There are many different strategies and philosophies on how to provide effective intervention. Just look back at Volume 9, issue 4 (April, 2009) to the article that summarized current course offerings. There are so many choices, it's overwhelming!

Let's face it, most of us do not work on a formal feeding team.- We find ourselves flying solo in our client's homes, schools, private practices or in the hospital. One piece of advice I often give to clinicians is to put together your own informal team.

If you can create your own "virtual team" whether it be local professionals to consult with or experts you can reach out to for collaboration—it will improve your success.

You can not approach pediatric feeding problems from one perspective alone. Think like a team!

The Pediatric Feeding & Dysphagia Newsletter
Hiro Publishing
321 Booth Rd.
Chapel Hill, NC 27516
919-357-4575

**Volume 10, number 1,
March, 2010**

Special Points of Interest:

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

Editorial assistance provided by John Brackett, Ph.D.



Inside this issue:

Editorial	1
Intensive Feeding Article	2-8
Current Job Opening	7
Autism and Feeding Chapter Excerpt	8-14
Case by Case	11-12
Current Research	18

Contact info: Krisi Brackett MS SLP/CCC, Hiro Publishing
321 Booth Rd., Chapel hill, NC 27516
feedingnewsletter@gmail.com 919-357-4575



The decision making process involved in determining where and how a child with a feeding disorder should be treated can be an overwhelming and complicated task. In fact, among professionals, medical providers, therapists within school settings, and communities at large, vast differences exist regarding interpretations, recommendations, and decision making processes when it comes to highlighting where a child should receive treatment. The answer to this question is likely different depending on the history of the child, medical status, nutritional status and how the child is nutritionally maintained, oral-sensory-motor development, history with therapeutic interventions, psychological associations developed with eating, degree of behavioral disruption, and overall family mental health. In addition to all of these contributing factors, availability of treatment options in a particular geographic region likely contributes to this decision making process.

As part of this decision making process, we at the Helen DeVos Children's Hospital Intensive Feeding Program (HDVCH), in Grand Rapids, Michigan, are often called upon to help determine how a child with a feeding disorder should approach treatment. With this task at hand, we often make multiple recommendations including but not limited to: additional medical assessment, traditional outpatient feeding therapy, nutritional counseling, outpatient psychological services, or a combination thereof. At times, we also recommend an intensive feeding program to comprehensively address the multiple needs of an individual child as a team and all at once. The following is a description of how we see each discipline's role in the comprehensive treatment of a child with a feeding disorder, how we work as a cohesive unit, and how the aspects of a multidisciplinary, multifaceted treatment team come together to make specific, measurable, and tangible changes to a child's feeding.

Who is a part of the multidisciplinary treatment team?

As part of our intensive feeding program, we rely on multiple individuals to help each discipline carry out core functions. This team includes a neurodevelopmental pediatrician, psychologists, nurse practitioner, occupational therapists, speech and language pathologists, feeding technicians, registered dietitians, pediatric culinary technician, medical social worker, child life specialist, case-manager/insurance verification specialist, and data analyst. In order to highlight what we see as the primary roles of the core disciplines, we will describe the unique contributions of several disciplines and offer specific examples of how each discipline was central to the feeding improvements with one specific patient, "Jack".

Medical

A thorough medical evaluation is important before any treatment plan can be determined for a child with a feeding disorder. At HDVCH, the medical evaluation is led by the Medical Director who is a neurodevelopmental pediatrician. The medical evaluation helps determine what other testing should be done to uncover physiologic problems that may impact feeding. At HDVCH the neurodevelopmental pediatrician has expertise in evaluating children with a wide range of issues related to premature births, genetic syndromes, muscle and motor disorders, and global developmental delays. Children with any of these disorders often have feeding and physical growth problems, and their success with feeding is an important part of a neurodevelopmental assessment. Many of our patients have these issues, but there are others who had untreated or unrecognized gastroesophageal reflux as their main problem which made early feedings very uncomfortable and interfered with becoming a successful eater.

As a result of the initial medical evaluation, a number of tests may need to be completed. To further evaluate the function of the GI tract, the following tests may be ordered: Upper GI to verify normal anatomy, gastric emptying scan to assess the movement of food out of the stomach, pH probe to quantify reflux, esophagogastroduodenoscopy or EGD where biopsies can be obtained to assess for celiac disease, eosinophilic esophagitis, and reflux. A video fluoroscopic swallow study (VFSS) or fiberoptic endoscopic evaluation of swallowing (FEES) are the tests used to verify safe swallow for food and liquid. A number of laboratory tests are often ordered to assess overall nutrition status and to rule out diseases that affect physical growth such as celiac disease, cystic fibrosis, and kidney disease. An MRI of the brain may

(Continued on page 3)

(Continued from page 2)

be ordered to assess normal anatomy and to rule out chiari malformations which can affect swallowing. The medical team may also make recommendations to rearrange the child's feeding schedule and volumes in order to improve tolerance of feedings and facilitate growth. If there are concerns that gastroesophageal reflux, GI dysmotility, GI pain, and/or constipation are untreated, medication therapy is started once the medical tests are completed.

The pediatric nurse practitioner (PNP) on the team sees each child at regular intervals in collaboration with the neurodevelopmental pediatrician after the initial team evaluation until they are admitted into the treatment program. The purpose for the follow-up visits is to be sure that medical problems are being treated or resolved, that the child is gaining weight, tolerating medication therapy, and completing any preadmission testing or ordered therapies. Once the child is admitted into the program, the PNP serves as the on-site medical provider to deal with routine health concerns, as well as to collaborate with the team to make changes in food and fluid volumes, and monitor for symptoms of feeding intolerance.

Jack was 2 years old at the time he entered the Intensive Feeding Program. Jack was born with a very significant medical problem which affected his feeding. He was born with a giant omphalocele. The repair of this condition involved complicated multi-staged surgery and he developed post operative complications involving GI tract functioning and the cardiorespiratory systems. He had multiple admissions to the hospital, several with prolonged periods of time on a ventilator. He did not eat well orally and was gastrostomy dependent by the time he was seen for his first team evaluation. Despite having a gastrostomy tube and receiving a Nissen fundoplication for his significant reflux, he had intolerance of volume into the stomach and was fed for a period of time into his small intestine. When the feeding team saw him for his first evaluation he was able to tolerate small boluses and a night time drip, but experienced gagging and retching with these feedings often. One of the initial goals for the team was to get him comfortable with his feedings through the GTube. Our motto has always been that if the GI tract is not "happy", feeding by mouth will be difficult to achieve. With the help of the dietitian who initiated adding baby food to his tube feeding, and by changing the focus of his outpatient feeding therapy from one of getting food and liquid into his mouth at all costs to skill development, by the time Jack came into the treatment program his body was ready for intensive treatment which ultimately made him successful and able to be weaned from his GTube dependence.

Nutrition

The primary role of the registered dietitian in the Intensive Feeding Program is to assess the child's growth, the nutritional adequacy of the child's intake, and the adequacy of the child's fluid intake. Most children are fed by mouth, by various tube-feeding delivery systems, or a combination of the two. In the evaluation clinic, each child's intake is assessed through parent report or written food logs. The intake is evaluated for calories, vitamins and minerals, and fluid. Nutrition recommendations are then made based on this evaluation. The dietitian is not only looking at the quantity in the meals or feedings, but also the quality of these feedings. Often, the child is growing well and has adequate intake, however, the quality of the meals or feedings is not appropriate. This is especially true for some of the tube-fed children. Gagging, retching, and volume intolerance are often reported.

When Jack was first evaluated in the clinic at 17 months of age, he was primarily G-tube fed. He had a history of formula intolerance and was still on a combination of the infant formulas Alimentum, Similac Advance powder, and safflower oil. He was given 3 boluses during the day and a night time drip. Parents reported that Jack often had problems with gagging in the morning. He was eating minimal amounts of food. Recommendations were made to transition Jack's tube feedings to a combination of a toddler formula and pureed solids (blenderized tube-feeding) and to eliminate

(Continued on page 4)

(Continued from page 3)

the night time drip. The reason solids were added to Jack's tube feeding was to improve tolerance to the tube feedings, and expose Jack to a variety of solids since he was not eating much orally. Weekly phone conversations were set up with the dietitian and family to make this transition. Soon after Stage 1 vegetables and fruits were introduced into the tube feedings, parents reported that Jack started to eat these foods by mouth. By the time Jack entered the day treatment Intensive Feeding Program he was tolerating five boluses a day of a combination Boost Kids Essentials 1.5, yogurt, safflower oil, and pureed meat, fruits, and vegetables with minimal gagging.

Once the child comes into the program, the registered dietitian continues to evaluate the adequacy of the child's nutritional and fluid intake. The dietitian also weighs and measures the child, develops the child's menu, assists in development of recipes, sets final goals for volume of food, drink and tube feedings, and provides nutritional education to the families. As Jack went through the Intensive Feeding Program, Jack's tube feedings were weaned from 900 milliliters to 90 milliliters at discharge. The remainder of the tube feeding was discontinued two weeks after discharge. Since discharge, the dietitian has remained in telephone contact with the family. The family has been able to increase food and drink volumes to ensure adequate growth.

Oral-Sensory-Motor

The role of the occupational and speech therapist with this team is to assess feeding and oral motor skills, design oral motor exercises to target specific skill deficits, and select appropriate food textures from a sensory and physiological perspective. Selection of seating for optimal support and position, drinking systems, and feeding utensils are also an important part of their roles. In this program, the speech therapist conducts FEES and VFSS assessments to determine safety as appropriate. When a child's sensory needs impact the feeding process, the occupational therapist completes a Sensory Evaluation and sets up Sensory Diets to complete throughout the day while the patient is in the program. Seating evaluations for feeding chairs are also completed by the occupational therapist. If fine and gross motor, sensory, and speech needs that are not related to feeding are determined, recommendations for outpatient services are made.

In Jack's case, specific Beckman oral motor exercises were chosen to target muscle weakness and discoordination of the cheeks, lips, and jaw. Jack also demonstrated oral hypersensitivity and anxiety when food or liquid was present on his hands or face. He rarely would accept any food or liquid in his mouth giving him very little experience with eating or drinking orally. The speech and occupational therapists offered recommendations to the team about Jack's oral motor ability and the degree of his sensory aversion to eating. At the initiation of treatment, food was not presented to Jack because of his severe oral aversion. Instead of offering food, the therapists worked with Jack on becoming comfortable with allowing a therapist to touch the outside of his mouth and progressed to assisting him in opening and closing his mouth with a verbal command. Eventually, dry feeding utensils were introduced into Jack's mouth while he willingly opened and closed. Over time, food and liquid were introduced in a very slow and systematic progression. When Jack was ready to accept food and liquid, smooth purees were chosen for a food texture due to his Jack's oral motor deficits and sensory defensiveness. Honey thickened liquids were chosen for safety as a result of a previous VFSS. A highchair with a five point harness system was chosen to give Jack a well-supported trunk and head while providing foot support for a developmentally appropriate feeding position. Jack was not able to functionally suck from a sippy cup or a straw, so a squeeze bottle was chosen for his liquid intake. The squeeze bottle allowed the therapists to control the size and placement of the liquid bolus in the Jack's mouth. This allowed Jack to take liquid without the use of a gastrostomy tube despite his oral motor deficits. Over time Jack learned how to control and swallow the liquid in his mouth, an important step toward independent drinking. The first spoon introduced was a soft EZ Spoon because of its small, narrow size with flat bowl. A side placement technique with the EZ Spoon allowed therapists to avoid touching Jack's sensitive tongue while still depositing food into his mouth. Jack progressed from dry trials with the EZ Spoon with side placement to eat-

(Continued on page 5)

(Continued from page 4)

ing very small volumes of food and liquid with these utensils and eventually to eating all of his food via a regular toddler sized spoon with midline placement.

Social Work

All children enter the Intensive Feeding Program with unique challenges for their family unit. Given the frequency, duration, and overall intensity of treatment, many day-to-day stressors exist for a family who has a child in an intensive feeding program. The role of the medical social worker in this Intensive Feeding Program is to provide psychosocial support to the child and family before, during, and after treatment. Prior to admission, the medical social worker completes a comprehensive psychosocial assessment of the family system. This assessment evaluates areas such as the makeup of the family unit, employment, finances, spirituality, culture, mental and physical health, learning needs, and current support system. Using this information, the social worker is able to identify both strengths and challenges for the patient and his/her family, and these characteristics are taken into consideration throughout treatment and discharge planning.

The medical social worker is responsible for identifying and intervening in situations where psychosocial stress could become a barrier to the child's feeding treatment plan. Appropriately addressing these challenges has potential to improve caregiver compliance, sustainability of the child's treatment gains, and maintenance of the child's overall participation in the intensive feeding program. Examples of unique family challenges which may need to be addressed include: caregiver mental health (anxiety, depression, grief and loss, guilt, and isolation are common themes), child custody issues (facilitating treatment and planning for discharge when the child has more than one home), and financial issues (assisting caregivers with budgeting strategies, evaluating the family's ability to purchase program-recommended food or supplies, and/or linking families with community resources such as food pantries and government programs). The medical social worker provides assistance to caregivers either individually or as a couple, providing assessment, counseling, case management, and support for the many unique strengths and challenges that make up the families of patients whom we serve.

Finally, the medical social worker participates with the entire treatment team in discharge planning to prepare for the child's transition back into their home, extended family, school, and community. The medical social worker may facilitate conversation with the child's daycare or school provider, make referrals for ongoing parent or family support, or help schedule any necessary training for extended providers who are vital to the child's care.

For Jack, his family had a number of strengths from which they drew upon. Overall family stability was identified. Jack had a nuclear two-parent home with significant extended family support. Both of Jack's parents presented as a cohesive unit and equally recognized Jack's feeding problems and were committed to participating in treatment. Jack's family resided several hours from the treatment facility, however the availability of extended family members provided both emotional support as well as local housing. Employment and financial stability allowed both parents to access a flexible work schedule, access FMLA, as well as some paid time off. Using these strengths, both parents were able to share in the responsibilities of Jack's treatment in the Intensive Feeding Program as well as attend to the ongoing needs of Jack's sibling. Discharge planning required minimal intervention, as he was not yet enrolled in school-based education and his parents provided primary care throughout the week. At the time of his graduation from the program, Jack's parents were both fully trained and well-prepared to teach other relatives and respite caregivers about Jack's mealtime routine.

Psychological

Our treatment program is theoretically grounded by the principles of applied behavior analysis and behavior modification.

(Continued on page 6)

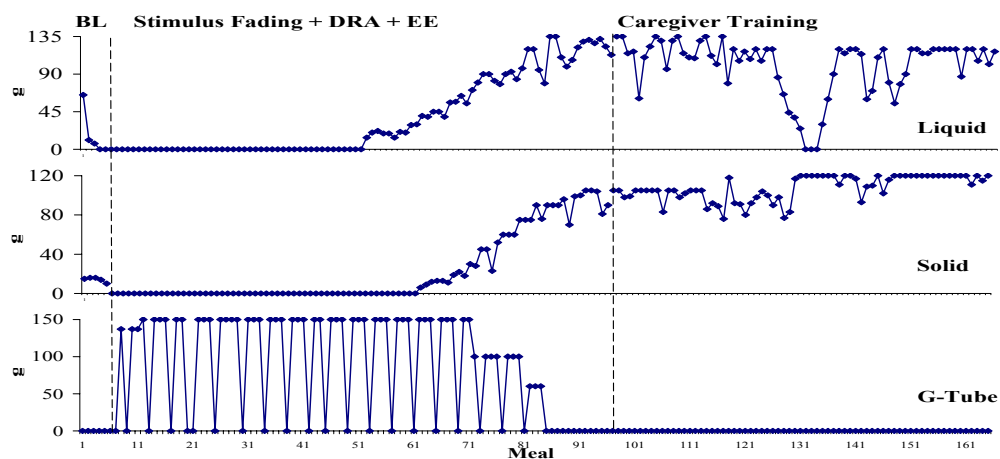
(Continued from page 5)

Psychology's unique contribution focuses on guiding the team to conduct baseline sessions as a child enters treatment in order to determine the function of problem meal time behaviors. Specifically, we attempt to assess if a child's refusal is maintained by escape, attention, access to tangibles, or to oral motor deficits. Following assessment, we determine whether a child can begin treatment with presentations of food and/or liquid, whether treatment needs to be initiated via shaping of prerequisite behaviors for eating, and guide the team how and when to progress to the next step in the necessary chain of required behaviors for successful oral intake. A specific and individualized behavior modification plan is established for each child focused on implementing a variety of strategies including exposure, escape extinction techniques, differential reinforcement of alternative behaviors, and overall teaching a child how to break his/her negatively learned aversions. Likely most importantly, we guide the treatment team to collect data on the child's behavior throughout each meal. Data is maintained on acceptance, expelling, pocketing, emesis, gagging, coughing, negative vocalizations, and other inappropriate behaviors. All changes in the treatment protocol are guided by this data.

As part of this process, psychology spends a significant amount of time educating parents/caregivers regarding learning principles and how problem feeding behaviors may be maintained. Caregivers are initially removed from feeding sessions and observe treatment sessions via a one-way mirror. Throughout this time, interpretation of strategies are offered and caregivers are trained in how to implement the feeding strategies. Psychologists will work with families regarding their understanding of the strategies and address other problem behaviors as they relate to feeding. Caregiver training is essential for generalization and maintenance of treatment gains.

In Jack's case, his baseline data revealed that he consumed an average of 10.14 grams of food per scheduled feeding and an average of 11.86 grams of liquid per scheduled feeding by mouth. No food or drink was initially offered. Throughout baseline, Jack had the tendency to snap at the spoon, turn his head away, and wipe his mouth following every bite. A wide open mouth for acceptance of a bite of food or sip of liquid was rarely, if ever observed. Initially, treatment goals included orienting Jack to the feeding process and routine. Given his refusal to consistently open his mouth on command, accept a spoon into his mouth far enough for bite acceptance, sustain an open mouth, or accept a drinking utensil (e.g., a cup) from a feeder, meals were initially presented without food or drink. Rather, Jack's behavior was shaped to tolerate handling for an open mouth, dry spoon, and dry squeeze bottle presentations.

According to his data over the course of treatment, Jack demonstrated a 94.75% acceptance rate of all food offered (92.66% in clinic; 98.66% home) and an 87.72% acceptance rate of all liquid offered (85.98% clinic; 90.52% home). This corresponded with an average of 97.96 grams of food per feeding (90.48 grams in clinic; 113.89 grams at home) and 100.19 grams of liquid per feeding (98.63 grams in clinic; 142.87 grams at home). A graphic representation of his progress is noted below.



Jack

	Avg. PO Intake /		Avg. % Oral Acceptance / Meal	Avg. G-tube Intake / Day (g)	# Preferred Foods
	Food (g)	Liquid (g)			
Baseline n = 7 meals	10	10	55	900 /1 Day	0
Final Tx Week n = 20 meals	116	104	90	90/ 7 Days	13

Discussion

While there are many treatment approaches and venues in which children with feeding disorders can be treated, we believe that there are times that an intensive, multidisciplinary treatment team is one treatment modality that offers a unique contribution of multiple disciplines. In Jack's case the results specifically highlight the unique and significant contributions of each discipline and we believe that his results would not have been possible without each discipline's involvement.

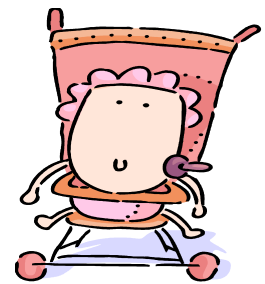
For more information, you can visit www.devoschildrens.org or email michelle.mastin@devoschildrens.org

The **Helen DeVos Children's Hospital Intensive Feeding Program** has 2 full-time openings for either a **Speech-Language Pathologist** OR an **Occupational Therapist**. This new multidisciplinary program is a collaborative venture in which inpatients are treated at Helen DeVos Children's Hospital and outpatients are treated at Mary Free Bed Rehabilitation Hospital.

The ideal candidate will have the ability to evaluate and treat children with feeding difficulties and their families, clinical experience in pediatric dysphagia, three years experience in a pediatric setting, CPR certification, excellent interpersonal skills working with people of diverse backgrounds and ages, good organizational and problem-solving skills as well as being a team player in a fast paced environment.

Speech-Language Pathologist: MA/MS from an ASHA accredited program, SLP-CCC, Occupational Therapist: NBCOT and state of MI licensures

Mary Free Bed offers a challenging and professional work environment and a competitive compensation/benefit package. For more information, please contact maryann.heinen@maryfreebed.com or 616-242-0488. Apply online at www.maryfreebed.com



Nutritional Problems

Nutrition is often overlooked as a possible contributing factor to a child's feeding problem. Something as simple as an excess amount of juice can displace food and the child does not have an appetite to consume solid food at meal-time because their stomach is full. Juice should be limited to 4 - 6 ounces per day, but many children consume much more. It is not uncommon for a child to sip on juice throughout the day drinking as much as 32 - 48 ounces per day. If the child is drinking an excess amount of juice, I suggest to gradually decrease the total amount to less than one cup per day. Parents may find that this not only improves the child's appetite but also his loose stools.

Nutrient deficiencies also contribute to feeding problems. A common symptom of vitamin and mineral deficiencies is loss of appetite. (A deficiency especially in zinc negatively impacts the child resulting in poor appetite contributing to feeding problems.) Deficiencies of other vitamins and mineral can have global symptoms such as irritability, mood and behavior changes, decreased attention, and lethargy, all of which can impact the child's ability to sit down at the table and eat a well-balanced meal. A poor diet contributes to nutrient deficiencies which in turn leads to poor appetite which results in food refusal and meal-time behavior problems. A Registered Dietitian can assess the child's diet to determine specific vitamin and mineral deficiencies and recommend appropriate supplements for the child.

Oral-Motor Dysfunction

Poor feeding skills related to sucking, lip closure, tongue lateralization, biting, chewing, and swallowing can result in the inability to handle foods of certain textures and consistencies. (When oral-motor problems occur, this interferes with the feeding process and food intake is limited.) A Speech and Language Pathologist (SLP) can evaluate the child's oral-motor function, identify delays and problems, and determine appropriate strategies and specific therapeutic activities to achieve improved feeding skills. The SLP may recommend interventions to strengthen the muscles of the mouth, increase tongue movement, improve chewing patterns, improve sucking and drinking ability, and increase tolerance of different foods and liquids. The child may also be referred for a video fluoroscopic swallow study also known as a modified barium swallow study to evaluate if the child is able to swallow safely without aspirating food or liquids into their lungs. It is important that children demonstrating feeding problems be assessed by a SLP to rule-out oral-motor problems prior to starting any feeding therapy program.

Sensory Integration Dysfunction

One of the most common contributing factors of feeding problems for autistic children is sensory integration dysfunction, also called sensory processing disorder. Children with sensory issues have difficulty processing and utilizing sensory input from their environment due to neurological differences that impact their reactions to all aspects of their daily life including eating. Eating food is very complex requiring all of our five senses: vision, touch, smell, taste, and hearing. The child must be able to integrate simultaneously all of his five senses during the eating process. A child with significant sensory

issues will have difficulties that impact their ability to eat. The child may be hypersensitive to texture, smells, and temperature of foods and become easily overwhelmed during mealtime and have a tantrum refusing to eat. The hypersensitive child can also overreact to noises and unable to eat at mealtime due to family members socializing and talking at the dinner table. Other children are sensory hyposensitive and receive too little sensory information resulting in behaviors that are sensory seeking. These children often stuff their mouth full of food, pocket food in the side of their mouth, and swallow the food later or spit it out.

If the child has sensory issues, common responses to expect during mealtime include:

Visual - The child may prefer foods of a certain color such as beige and reject foods of any other color. He may have a tantrum if foods touch each other on the plate. Serving sizes too large can visually overwhelm the child and he may totally refuse to eat anything.

Tactile - The child with tactile hypersensitivity often are unwilling to touch foods with their hands. Exploring foods with their hands is a critical step to become familiar with a new food, put the food to their mouth, and learns to successfully eat the food. The tactile hypersensitive child will reject new foods, gag, choke, or vomit which continues to reinforce their fear of certain foods.

Smell - Hypersensitivity to smells can cause problems with the child during the cooking preparation where he becomes fussy and progresses to being totally overwhelmed by the odors before mealtime even begins. He may gag or vomit when the food is offered at mealtime.

Taste - Strong flavors can trigger the gag reflex in children with taste hypersensitivity. He will tend to have very strong taste preferences, preferring bland foods or specific flavors.

Auditory - Eating food itself creates sounds that are overwhelming to the child. He may prefer soft foods and liquids to avoid the sounds created by hard crunchy foods. People talking at the dinner table, sounds in the environment, T.V., and other sounds during meal-time can distract the child and he may be unable to eat.

An Occupational Therapist (OT) can evaluate the child's ability to process sensory information, assess if he has a sensory integration dysfunction, and how it impacts his ability to eat. The OT plays a major role in developing a treatment program, providing therapy, and improving the child's tolerance level to sensory input.

Environmental Factors

When assessing the child's feeding problem, it is important to consider environmental factors that are contributing to the problem such as,

Distractions during mealtime can over stimulate the child; he may become overwhelmed from the sensory overload, lose focus, and become disinterested in eating. It is important to keep distractions at mealtime to a minimum by limiting noise and turning off the television set.

Grazing throughout the day will cause the child to lose their internal biorhythm of feeling hunger then full. He will not develop normal hunger cues and will not have a desire to sit down and eat a meal or healthy snack.

Lack of routine results in the child not being able to fall into a daily pattern that helps the child know when to expect a meal or snack. Children should have a structured daily schedule that includes three meals and two to three snacks everyday. Meals and snacks should be offered to the child at a designated place where the child is expected to sit in a chair at a table. Consistency, structure, and routine developed around mealtime and snacks will promote a healthy appetite and improved eating.

Mealtime dynamics between the child and parents needs to be observed and determined if the parents are unknowingly doing something inappropriate that is making the feeding problem worse. Common mistakes that parents make are to coerce, trick, or bribe their child to taste a food. This can lead to struggles between the parents and their child and make the feeding problem worse.

Poor physical environment itself contributes to feeding problems. Where the child sits, an appropriate chair, posture during mealtime, and age appropriate utensils all need to be assessed to assure they meet the needs of the child.

I encourage one of the child's therapists and or Behavioral Therapist to go to the child's home and observe a mealtime. The therapist may detect important environment factors that need to be addressed and strategies to include in the child's feeding intervention plan.

Behavioral Problems

Some of the child's behaviors may interfere with his ability to eat a meal. It is important to pay attention to the child's mealtime behavior and figure out what he is trying to tell you. This is especially important for a child who is non-verbal or a child who has problems with expressive language. Negative behaviors are often a form of communication. Common negative mealtime behaviors include refusing to come to the table, will not sit still in his chair and leaves the table, refuses to eat, throws food, crying, tantrums, gagging, and vomiting. It is important to first rule-out contributing factors such as medical conditions, nutritional problems, oral-motor dysfunction, sensory integration dysfunction, and environmental factors that may be contributing to the child's negative behaviors. Medical conditions such as gastrointestinal problems often result in food refusal or the child willing to even come to the table because he has connected that food equals physical pain. Certain medications can diminish the child's appetite and he may have no desire to sit down and eat a meal. The child with sensory integration dysfunction who becomes easily overwhelmed by his environment may become very frustrated at mealtime refusing to eat, cry, tantrum, gag, or vomit. A hyperactive child with a short attention span will have difficulty sitting still in his chair, become highly distracted, lose interest in the meal, and leave the table. Oral-motor problems make it difficult for the child to eat certain foods and textures and he may

refuse, spit out, choke, or gag on these foods. Nutritional deficiencies and excess intake of juice will interfere with the child's appetite and he may avoid coming to the table at mealtime, refuse to eat, and leave the table without eating. Once these contributing factors have been identified and treated, feeding problems and behavioral issues at mealtime may significantly improve. However, because these responses are so entrenched in the child's mealtime routine, he may continue these negative behaviors.

It will be critical for the child to be assessed by a Behavioral Specialist. The Behavioral Specialist will conduct a behavioral functional assessment to help determine what triggers specific behaviors at mealtime and develop strategies for the parent to handle the child's behavior. He will also provide essential technical assistance to the child's therapists on how to handle the behavior problems and advise on developing a feeding intervention plan.

FEEDING THERAPY PROGRAMS

If you suspect a child is a problem feeder, it is crucial to build a multidisciplinary feeding team of appropriate professionals to conduct evaluations, identify factors contributing to the feeding problem, and develop a feeding intervention plan, before starting feeding therapy sessions. The feeding team will consist of a Physician, Speech-Language Pathologist, Occupational Therapist, Registered Dietitian, and Behavioral Specialist. A multidisciplinary approach is necessary to work with feeding problems because they require the expertise of various professionals and each team member has a unique role to play. The Physician will be responsible for the medical exam to identify and then treat any medical conditions that may be contributing to the feeding problem. Each of the other therapists; Speech-Language Pathologist, Occupational Therapist, Registered Dietitian, and Behavioral Specialist will each conduct their own evaluation to assess the child's feeding. Based on the results of each of the evaluations, it may be determined that the child does have feeding problems that warrant ongoing individualized feeding therapy sessions. The feeding team will develop a Feeding Intervention Plan that includes some the following information:

- Factors contributing to the child's feeding problem
- Strategies to address each of the contributing factors
- Specific feeding treatment approaches
- Frequency of feeding therapy sessions
- Outcome goals for treatment and how to measure progress
- Which therapist will provide the actual feeding therapy
- Mode of communication between feeding team members

There is very little research about effective feeding therapy to treat feeding problems among young children with autism and even less information available regarding working with older children. However, there are step-by-step feeding therapy programs that have been quite successful with autistic children. Parents should discuss these treatment approaches with their feeding team. One step-by-

step program is called *"Food Chaining"*. Food chaining is based on the idea that there are specific reasons why the child will eat only certain foods. The child finds these foods acceptable maybe because of the color, texture, flavor, or just visual appearance. Food chaining determines why the child accepts these foods, and then you expand his food repertoire by introducing new foods that have the same features as the foods he currently eats. After the child has expanded his diet from this method, more new foods are introduced that are slightly different. For more information on food chaining, refer to the book: *"Food Chaining The Proven 6-Step Plan to Stop Picky Eating, Solve Feeding Problems, and Expand Your Child's Diet"* by Cheri Fraker, Laura Walbert, Sibyl Cox, and Mark Fishbein.

Another step-by-step program is called the *"Sequential Oral Sensory (SOS) Approach to Feeding"*. The SOS approach is a multidisciplinary feeding program which is based on 32 steps to eating a new food including tolerate, interact, smell, touch, taste, and eat. It was developed by Dr. Kay Toomey, Ph.D., Pediatric Psychologist located in Denver Colorado who provides advanced courses to train therapists in the SOS Approach.

FINDING A FEEDING TEAM

Many hospitals, medical facilities, and private clinics in large cities have feeding teams already in place. However, this may not be a viable option for a family because the feeding team is too far away from where they live. Due to the distance, it is not realistic for the parents to drive their child back and forth for weeks and possibly months of ongoing feeding therapy sessions. If the family lives in a smaller town, there may be no feeding team in place even at the local hospital. In reality, most families find that there is not a multidisciplinary feeding team available in their local community that is easily accessible. So, the parents will need to assemble a feeding team themselves. Parents can start by asking their child's Physician for a referral to various therapists. Parents then start identifying individual providers who are willing to fill the multidisciplinary roles as the Speech-Language Pathologist, Occupational Therapist, Registered Dietitian, and Behavioral Specialist. These providers may be the therapist currently providing services to the child or other therapists in their community who have experience with feeding problems. While, parents may think that building a multidisciplinary feeding team for their child is overwhelming, it is absolutely critical to achieve the goal of resolving the child's feeding problem and expanding his diet.

AT-HOME STRATEGIES TO IMPROVE THE CHILD'S FEEDING PROBLEM

Assembling a multidisciplinary team, obtaining evaluations from each team member, scheduling a medical exam with the physician, developing a feeding intervention plan, and initiating feeding therapy sessions will take an extensive length of time. During this process, I encourage parents to start with the very basic strategies to improve their child's feeding. These strategies include:

Positive reinforcement - Verbally reinforce the child when he does something appropriate at mealtime. Also reinforce appropriate eating behavior of any sibling. Keep mealtime positive, pleasant and enjoyable.

Social modeling - Have the child sit at the dinner table with the rest of the family at mealtime. Parents and siblings should model good eating and social behavior and avoid making negative com-

ments and faces at foods. The child should not be the focus of the mealtime.

Limit juice - Decrease juice intake to less than one cup per day.

Do not allow grazing throughout the day - Offer the child three meals plus three small snacks per day. Between meals and snacks the child may have water. Do not allow the child to nibble on small amounts of food throughout the day.

Structured meals and snacks - Meals and snacks should be approximately 2 $\frac{1}{2}$ - 3 hours apart from each other and offered at consistent times and at the same place in the home. Children need to learn that there is a daily routine involved with meals and snacks. Meals should be limited to no more than 30 minutes and snacks to 15 minutes.

Limit distractions during mealtime - Turn off the television during meals and limit excess noises to avoid auditory over stimulation.

Offer manageable foods - Present foods on the child's plate in small, easily chewable bites. Limit the number of different foods on his plate to three items. Limit the volume of food on his plate to smaller than normal serving sizes to avoid visual over stimulation.

Involve child in menu planning, grocery shopping, food prep, set table - Children are more likely to eat a food if he has been involved in some sort of interaction with the food prior to mealtime.

Use appropriate mealtime language - Do not ask the child a question or make a demand that can be responded with a "no" and lead to a power struggle between the parent and their child. Avoid "can you" questions and "don't" demands. Instead, speak to child in concrete terms, "you can" and "do".

Example: "Suzie, can you take a bite of peas for momma?" Replace with, "Suzie eats peas with her spoon."

Example: "Suzie, please can you drink some milk for daddy?" Replace with, "Suzie sips milk from her cup."

Example: "Don't throw your cup!" Replace with, "Cups are for drinking, your cup goes here, until you are ready for a sip."

Example: "Don't put so many crackers in your mouth at a time, you're going to choke!" Replace with, "Johnnie chews one cracker at a time."

Avoid food burnout - Eating the same food, the same way, every day will lead to "burn-out" and the child will eventually eliminate the food from his diet. Once an autistic child with a feeding problem eliminates a preferred food, he usually does not accept it again in the future. If this process continues, the child will eventually be left with only a very few foods in his diet. Tips to avoid "burn-out" include:

Offer a particular food no more than every other day.

2. If the child has a very limited variety of foods and the particular food has to be offered daily, change on thing about the color, shape, texture, or taste of the food. The change should be very slight so the child notices a difference but not enough to cause the child to reject the food; but different enough to where the child is less likely to "burn-out" on the food.

Excerpt from a New Book! Part 2:

Autism and Feeding Problems by: Elizabeth Strickland, RD, LD

Example: Suzie eats a pancake every day, her diet is limited to 3 foods, mom can not eliminate pancakes so she must continue to offer pancakes daily and avoid "burn-out" at the same time.

Monday: Serve pancake as usual.

Tuesday: Change the shape; oblong not perfectly round.

Wednesday: Change the taste; add two eggs in the batter instead of one.

Thursday: Change the texture; add a very small amount of fiber powder to the batter.

Friday: Change the color; add small amount of fruit preserves to the batter.

Saturday: Change the shape of the butter on the pancake.

Sunday: Change the color of the syrup, darker or lighter.

These basic strategies will help improving the child's eating behaviors and hopefully prevent them from getting worse while the feeding team is being assembled and more individualized feeding strategies and therapy is initiated.

Summary

Please do not take the "wait and see" approach and hope the child's feeding problem improves on its own. If a feeding problem is not addressed early, it tends to progress and get worse over time. Feeding problems are very complex and require a multidisciplinary approach from a physician, speech-language pathologist, occupational therapist, behavioral specialist, and registered dietitian. It is important to remember that parents are not feeding therapist and should not be put in the position to assume this role. Children with feeding problems must be referred to a multidisciplinary feeding team for assessment and appropriate individualized feeding therapy sessions. Addressing an autistic child's feeding problem is challenging, time consuming, and usually takes weeks to months to achieve success. However, when the child's diet expands and he is eating a variety of healthy foods, it will be well worth all your time, effort, and hard work.

Elizabeth Strickland, MS, RD, LD is a Registered Dietitian with special interest in integrative and holistic medicine, whole foods, dietary supplements, and natural healing treatment methods. Elizabeth practices integrative nutrition therapy to help treat autism, Asperger's, ADHD, PDD, ADD, sensory processing disorders, learning disabilities, and other related disorders. She has over 25 years of experience ranging from providing individual nutrition therapy and presenting nutrition seminars to professionals and parents. To contact Elizabeth, email her at ASDpuzzle@aol.com or refer to her website at www.ASDpuzzle.com. For more detailed information on nutrition and feeding interventions for autism, refer to Elizabeth's book, *"Eating for Autism ... The 10 - Step Nutrition Plan to Help Treat Autism, Asperger's, or ADHD"*. It is available at www.amazon.com and any major bookstore.

Book website: www.Eating-For-Autism.com.

Case by Case: Weaning Naso-gastric Fed Respiratory-dependent Infants

By Judith Blinder, SLP, Eliezer Be'eri, MD and Mauritz Beerli, MD MPA.

Background

The Respiratory Rehabilitation Unit at Alyn Hospital is a 19-bed inpatient facility that provides multidisciplinary rehabilitation treatment from infancy to adolescence including children who are ventilator and/or tracheotomy dependent. The unit serves as a tertiary referral center from intensive care units around the country, treating a spectrum of chronic respiratory disorders ranging from bronchopulmonary dysplasia in post-prematurity infants to high cervical quadriplegics.

History

MB was delivered premature in the 25th week of pregnancy, weighing 26 ounces. He developed bronchopulmonary dysplasia which required prolonged ventilation, followed by severe laryngeal stenosis secondary to an intubation-induced granulomatous mass. Tracheostomy was performed at age 90 days. He was admitted to the Alyn Respiratory Rehabilitation Unit for weaning off the respirator at six months of age, weighing 7.9 pounds. MB was oxygen and diuretic dependent and was receiving Omeprazole for suspected gastro-esophageal reflux.

Feeding goals were set and monitored by a team that included the physicians, dietician, speech therapist, social worker, psychologist and nurse. The speech therapist was the designated case manager.

Feeding history

On admission, MB was breastfed with supplemental bottled formula. MB showed disorganized sucking with periodic oxygen desaturations during feeds. Due to lack of weight gain he required the insertion of a naso-gastric tube, which resulted in cessation of voluntary oral feedings. As a first step towards reintroducing oral feeds we established a feeding regime of continuous drip by night with the mother attempting oral feeds prior to NG bolus supplementation during the day. Thus weight gain was ensured while gradually increasing oral feed quantities to 2-3 oz per feed.

Intervention

During the period that MB was being weaned gradually off ventilation, he received intensive feeding therapy aimed to decrease oral sensitivity with oral motor exercises. The mother was instructed to provide proper jaw support to promote efficient sucking and to position the child correctly for optimal feeding. Food was gradually diversified to include age appropriate textures and tastes. A month after his admission, at age 7 months, spoon feeding of pureed food was added. At age 13 months, MB succeeded in being weaned off chronic ventilation though remained with a tracheostomy tube in place.

The decision to advance to complete weaning off NG feeds was based on a team evaluation after the following pre-set goals were reached:

1. Stable medical status (pulmonary, gastroenterology and neurological condition)
2. Child feeds regularly on close to age-appropriate food of palatable consistency and taste
3. Child acquired initial feeding skills

(Continued on page 16)

Case by Case...Weaning Naso-gastric Fed Respiratory-dependent Infants

By Judith Blinder, SLP, Eliezer Be'eri, MD and Mauritz Beerli, MD MPA.

(Continued from page 15)

4. The nutritional status allows up to 10% weight loss during weaning
5. Procedures and expectations were coordinated between the team and family.

Weaning: MB and his mother were hospitalized in a private room. The room had a high chair and table, and the mother was free to attend to MB's feeding needs. NG feeds were reduced by half on the first day and stopped altogether on the second. The mother fed him, coached by the team (daily physician and nurse rounds, two feeding sessions with the speech therapist every day, three weekly meetings with the psychologist, and input by the dietician twice a week). We limited weighing to twice a week, to minimize the expected distress at the inevitable weight loss. Urine density served as the marker to rule out dehydration.

The mealtime atmosphere was pleasant. We set no expectations as to what or how much MB ate. However, the mother was instructed to offer food only after the infant sent a clear signal. Within a few days, MB learned to express signals of thirst, hunger, and satiety. The rate and degree of oral stimulation, textures and tastes were continuously evaluated and discussed with the family according to MB's progress over the next two weeks.

Outcome:

MB went from 14.5 to 13.9 pounds in two weeks, losing 4% of his body weight and ending at the 5th percentile for corrected age. He regained the weight loss over the next 6 weeks.

Three months later, MB eats a diverse diet yet his oral motor skills are still lagging. He takes three meals of bottled 110% formula enriched with 3% MCT and 5% polycose, one meal of sweetened yohgurt and two meals of pureed vegetables with meat, bringing him to 120 kcal/kg body weight. He has begun enjoying finger-foods. Most importantly, meals are pleasant and stress-free.

Discussion:

The rehabilitation of oral feeding in a premature infant with severe lung disease after prolonged dependency on NG feeds is known to be challenging and frequently fails. Infants with BPD have a high prevalence of suck-swallow-breath coordination difficulties, often presenting as oxygen desaturation events during feeding. Decreased intake leads to poor growth and development. A high rate of gastroesophageal reflux in these children adds to the risk of esophagitis and secondary anorexia. Many children require a gastrostomy tube to ensure growth and development until their respiratory condition improves. Postponing oral feeds beyond 18 months of age makes later weaning even more difficult. Yet weaning is possible even in these cases provided all potential pitfalls have been dealt with prior to the intervention.

We identified several key issues as the pillars of successful weaning:

- a. The primary diagnosis and intervention focus must address the parent-infant interactive level (Dunitz and Sheer, 1997, 1998). The feeding relationship is an integral part of human attachment behavior and all care giving relationships (Chatoor et. al. 1997). When children are tube fed the interaction is disturbed and the development of the infant-parent interaction may become distorted.

(Continued on page 17)

Case by Case...Weaning Naso-gastric Fed Respiratory-dependent Infants

By Judith Blinder, SLP, Eliezer Be'eri, MD and Mauritz Beerli, MD MPA.

(Continued from page 16)

Success often depends on a parent's commitment and ongoing involvement. Sufficient attention and time must be allowed to deepen and strengthen the parental bond, often damaged by prolonged hospitalization, prior to the weaning. The parent must be prepared to assume full responsibility for the actual feeding while relying on the team's directions.

b. We recommend intensive oro-motor therapies: infants who experience painful or irritating oral interventions are at risk of developing later feeding aversion and oral sensitivity issues that hinder later feeding. Gaebler and Hanzlik (1996) showed that perioral and intraoral stimulation prior to oral feeding improve the scores on the NOMAS scale of infants and had a positive correlation with weight gain.

Oxygen desaturations can be prevented by the feeder with interventions such as pacing or slowing the rate of flow of the food through a carefully matched feeding teat. Later, proper spoon matching is important, as well as exposing the child as early as possible to age-appropriate foods, so that feeding skills will be as advanced as possible prior to weaning. However it is sometimes preferable to downplay direct oro-motor intervention during the weaning program so as to preserve a safe positive feedback environment and encourage feeding independence.

c. In MB's case, weaning off the NG tube was deferred until he was weaned off chronic ventilation. This does not have to be the case. However if weaning off chronic ventilation is a viable goal, the team needs to decide which of the two goals (weaning off ventilation or weaning off tube feeding) has the priority. Positive pressure ventilation, although not prohibitive of oral feeding, does change the sensory input significantly and may change swallowing patterns. Moreover, the weight loss which is expected during the NG weaning process is counter productive towards respiratory rehabilitation. Attempting to challenge the child by weaning off both interventions simultaneously is likely to result in the failure of both. If respiratory weaning is preferable, the team should concentrate on oro-motor preparedness until a decision is made to progress to NG weaning.

d. Feeding difficulties should not be expected to resolve completely after weaning. Long term follow-up by the speech therapist and dietician, the physician and the psychologist are necessary. Ongoing monitoring of the quality and quantity of feeds, the weight gain, the development and the feeding environment and social adjustment are all important.

The success of weaning depends on team work and the pre-weaning effort.

References

- Gaebler CP, Hanzlik JR. The effects of a prefeeding stimulation programme on preterm infants. *Am J Occ Ther* 1996; 50:184-192.
- Jones, E., King, C.,(2005). *Feeding and Nutrition in the Preterm Infant*. Elsevier Churchill Livingstone.
- Dunitz, M., Sheer, P., Schein, A., Wilken M.,(2008) "Lets get off the tube": Tube weaning in infancy. Judith Blinder, SLP, Eliezer Be'eri, MD and Mauritz Beerli, MD MPA. Alyn Hospital. Pediatric and Adolescent Rehabilitation Center. Jerusalem. Israel. judy@alyn.org

On the Research Front:

Woods JN, Borrero JC, Laud RB, Borrero CS. Descriptive analyses of pediatric food refusal: the structure of parental attention. Behav Modif. 2010 Jan;34(1):35-56.

Mealtime observations were conducted and the researchers recorded occurrences of appropriate and inappropriate mealtime behavior and various forms of parental attention (e.g., coaxing, reprimands). Results showed that parental attention was frequently followed by temporary decreases in inappropriate mealtime behavior and increases in bite acceptance. Moreover, various forms of parental attention resulted in statistically significant changes in child behavior, which supports the clinical utility of these data. PMID: 20051524

Mahachoklertwattana P, Wanasuwankul S, Poomthavorn P, Choubtum L, Sriphrapadang A. Short-term Cyproheptadine therapy in underweight children: effects on growth and serum insulin-like growth factor-I. J Pediatr Endocrinol Metab. 2009 May;22(5):425-32.

Cyproheptadine, an appetite stimulant, has been used in poor-appetite and underweight children. Its beneficial effects on enhancing growth rate have been demonstrated. In contrast, an adverse effect on blunting growth hormone (GH) secretion has also been reported. To date, however, its effect on insulinlike growth factor-I (IGF-I), a GH-mediated growth factor, has not been documented.

The authors examined the effects of cyproheptadine therapy on growth and serum IGF-I in underweight children. Results indicated that weight and height velocities and IGF-I z-scores during cyproheptadine therapy were significantly greater in the intervention group than those of the placebo group. Therefore, cyproheptadine therapy in underweight children increased caloric intake and serum IGF-I concentration and consequently enhanced growth velocity. PMID: 19618661

Buie T, Fuchs GJ 3rd, Furuta GT, Kooros K, Levy J, Lewis JD, Wershil BK, Winter H. Recommendations for evaluation and treatment of common gastrointestinal problems in children with ASDs. Pediatrics. 2010 Jan;125 Suppl 1:S19-29.

Children with autism spectrum disorders (ASDs) can benefit from adaptation of general pediatric guidelines for the diagnostic evaluation of abdominal pain, chronic constipation, and gastroesophageal reflux disease. These guidelines help health care providers determine when gastrointestinal symptoms are self-limited and when evaluation beyond a thorough medical history and physical examination should be considered. Children with ASDs who have gastrointestinal disorders may present with behavioral manifestations. Diagnostic and treatment recommendations for the general pediatric population are useful to consider until the development of evidence-based guidelines specifically for patients with ASDs. PMID: 20048084

Indrio F, Riezzo G, Raimondi F, Francavilla R, Montagna O, Valenzano ML, Cavallo L, Boehm G. Probiotics improve gastric motility and gastric electrical activity in preterm newborns. J Pediatr Gastroenterol Nutr. 2009 Aug;49(2):258-61.

The aim of this study was to evaluate the effect of a prebiotic mixture on gastric motility in preterm newborns. After a feeding period of 15 days, gastric electrical activity was measured by electrogastrography, and the gastric emptying time was studied by ultrasound technique. No difference was seen in the daily increase of body weight, and no adverse events have been reported. The gastric half-emptying time was 30% faster in the prebiotic group than the placebo group. Prebiotic oligosaccharides can modulate the electrical activity and the gastric emptying and may improve the intestinal tolerance of enteral feeding in preterm infants. PMID: 19561548