



Pediatric Feeding and Dysphagia Newsletter

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- Krisi Brackett MS SLP/CCC

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Velopharyngeal Incompetence and Feeding: What Every Feeding Therapist Should Know!

By Lisa H. Young, MS, CCC-SLP,
Department of Otolaryngology, Craniofacial Clinic, Riley Hospital for Children,
Indianapolis, IN

If you are a speech pathologist reading this article, you are most likely familiar with velopharyngeal incompetence (VPI) and how it affects speech by causing hypernasality. The effects on feeding and swallowing begin at a much earlier age, and many times are more difficult to identify. The purpose of this article is to familiarize Feeding Therapists of all disciplines to the anatomy and physiology of the velopharyngeal mechanism and to help in identifying feeding/swallowing issues related to VPI.

What is Velopharyngeal Incompetence?

The following are representations of the velopharyngeal mechanism. In order to build pressure for speech or negative pressure suction (for bottle or breast feeding), the soft palate (velum) must make contact with the posterior pharyngeal wall (back of throat). If this process does not happen sufficiently, velopharyngeal incompetence is present.

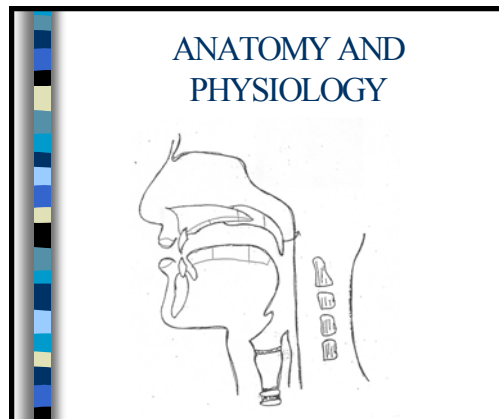
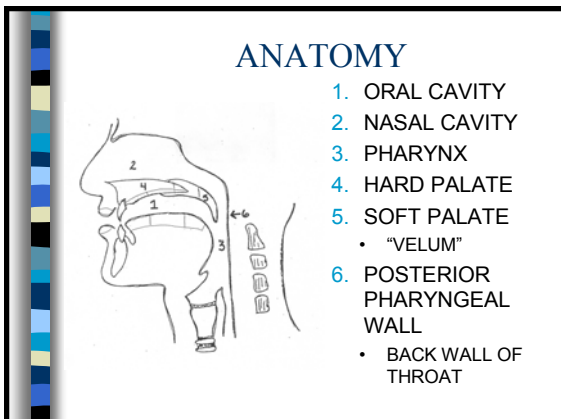
Special Points of Interest:

- 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

Inside this issue:

Velopharyngeal Incompetence	1-3
Recommendation	3
PAGER	4-5
Case by Case	6-8
Hydration and Tube Weaning	8-9
On the Research Front	9-10



Velopharyngeal Incompetence and Feeding: What Every Feeding Therapist Should Know! By Lisa H. Young, MS, CCC-SLP, Department of Otolaryngology, Craniofacial Clinic, Riley Hospital for Children, Indianapolis, IN

What are the causes of VPI?

There can be many reasons that VPI is present, with the most obvious being that the child is born with an open cleft palate. This is easily identifiable and will be diagnosed at birth.

The tricky times are when VPI is present and the child is born WITHOUT an open cleft. All too often, VPI is not considered as the primary reason for a feeding problem. There are two specific cases that are important to mention: 1) submucous clefting and 2) deep pharynx related to syndromes.

A submucous cleft is a cleft of the soft palate that is not open. The tissue of the soft palate does form and closes off the roof of the mouth, but the muscles behind that tissue do not integrate or work as they are supposed to. This causes dysfunction in the valving mechanism needed to form negative pressure for efficient bottle or breast feeding. Upon oral examination of these babies, many times you will observe a bifid uvula (split uvula, causing there to be the appearance of two uvulas), and sometimes a translucent line in the middle of the palate indicating that the musculature has not integrated throughout the palate. This translucent line is called a zona pellucida. Many times, submucous clefts are not identified at birth and even missed by primary physicians until there is a feeding or speech problem.

There can also be the presence of VPI without any type of clefting. This child gets missed all too often. Because the palate appears normal, VPI is usually not a consideration of differential diagnosis for a feeding or weight gain problem. There are many syndromes, namely Velocardiofacial syndrome or DiGeorge syndrome where the child may present with a normal palate, but their pharyngeal depth is too deep. In other words, the palate may be working, but it is unable to meet the back wall of the throat. There may also be palatal dysfunction present in these patients, mainly cranial nerve deficits causing asymmetrical or palatal immobility, which could result in VPI.

What types of feeding/swallowing problems would be present?

Because VPI causes reduced negative pressure in the oral mechanism, the main symptoms you will see will be a baby that presents with a very weak suck or may be unable to latch to the breast for breast milk. This would cause the baby to be unable to express milk from the bottle or breast efficiently. On oral exam, a weak suck may be felt on a gloved finger, or the seen in the baby's inability to hold a pacifier in mouth may be seen.

Parents may report excessive feeding times and fatigue with feeding. This may be because the baby cannot build efficient pressure and may be taking the bottle extremely slowly, while working very hard to express. This would ultimately express itself at Failure to Thrive (FTT) and poor weight gain. These children use more calories than they are taking in to express small amounts of food.

Parents may also report nasal regurgitation (liquid coming out of the nose during feeding). This is

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(Continued from page 2)

also a big red flag for VPI. This is also caused by insufficiency in the palate valving off the nasal cavity during swallowing. Prolonged nasal regurgitation will cause increased nasal congestion as well, adding to the difficulty in coordinating suck, swallow, breath during bottle or breastfeeding.

What do I do about it?

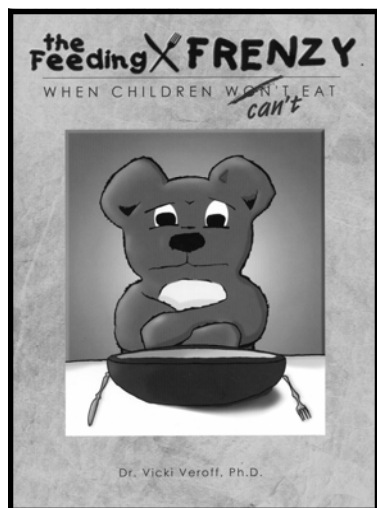
As feeding therapists, we must consider VPI as a possible cause for failure to thrive (FTT), poor weight gain, a weak suck, and excessive feeding times. It is all too often not considered as a differential diagnosis and many times, these babies receive alternative means of nutrition unnecessarily.

If VPI is suspected, a specialty bottle such as the Haberman or Pigeon should be introduced. These bottles will provide support that is needed due to an inefficient velopharyngeal mechanism. They can also increase intake and decrease feeding times, which will obviously help with weight gain and fatigue issues.

If a submucous cleft is even SUSPECTED, appropriate referrals to ENT should be made. There could also be other medical issues present, such as chronic otitis media with this condition that should be managed.

If more information is needed regarding cleft palate or craniofacial anomalies, contact the Cleft Palate Foundation at 1-800-242-5338.

Recommendations:



The Feeding Frenzy by Dr. Vicki Veroff, Ph.D.

This booklet is a guide for parents providing information about failure to thrive, feeding disorders, and how they are evaluated. It is written in parent friendly lingo and explains various types of feeding problems such as appetite disorder, problems with drinking, non-chewers, and picky/selective eaters. Each sections provides an explanation and offers treatment options. There is also a reference sections, suggested reading and a good bibliography. I enjoyed the book and would recommend it to families. It does not discuss treatment in depth (strategies suggested are largely oral motor and sensory), intensive feeding programs or behavioral strategies.

To order: Dr. Vicki Veroff tel: 514-626-7778
4309C Boul. St. Jean fax: 514-626-8553
Dollard des Ormeaux, QC
drveroff@feedingdisorders.com



The Pediatric Adolescent Gastroesophageal Reflux Association By Jan Burns, PAGER Association

The Pediatric Adolescent Gastroesophageal Reflux Association (PAGER Association) is a non profit organization dedicated to providing information and support to families of infants and children with gastroesophageal reflux or GER. Thirteen years ago, Beth Anderson was caring for her infant Katie and experienced severe reflux first hand. Katie cried and vomited constantly and refused to sleep at night. While these symptoms of GER are typical and reflux is considered a common medical condition, Beth felt isolated and wanted to find other parents with common concerns. Eventually Beth started a support group in her community and PAGER Association was born.

Most doctors and parents are familiar with the three “classic” GERD symptoms of extreme spitting up, extreme fussiness and failure to thrive. There are many subtler symptoms associated with reflux that are easier to miss. These symptoms include hiccups, bad breath, picky eating, poor sleep and aggression. In some cases, GER may lead to secondary complications such as extreme food selectivity, failure to thrive, respiratory problems, apnea, ear infections, swallowing disorders and dental erosion. Many infants and children with reflux require constant care including: special feeding techniques, frequent feeding, positioning, frequent burping, holding and comforting. Some parents report that they have had to bring in grandparents or a nanny because it is too exhausting to care for the baby alone. Beth Anderson coined the phrase “Intensive Care Parenting” to describe the 24/7 care required to take care of a medically complex/high need infant or child with reflux.

PAGER provides support through an information rich website (www.reflux.org) and supports a discussion board that is extremely busy! Parents in rural areas, outside of the US or who are too overwhelmed to get out of the house find that the discussion board is their lifeline to the world of reflux. Some parents hold their fussy baby with one hand while typing with the other in the middle of the long, long night.

Parents and family members are also encouraged to call the message center/warm line (301-601-9541) and request a call from a trained parent volunteer offering 1:1 support. Presently, PAGER has 30 trained volunteers with a variety of experiences. They have on the job training, courtesy of their children and several volunteers happen to be physical, occupational and speech therapists. All parent volunteers have been trained and offer a vital link to families.

PAGER membership supports a quarterly newsletter and many publications, videos and brochures offering practical information for families. Popular booklets including: Breastfeeding the infant with GERD, Focus on Feeding and Going to School with Acid Reflux. New members receive a large packet of materials, quarterly newsletters and advanced notice of conferences and meetings.

This year, PAGER received a grant to begin a class/support group model called: GERD 101: Parenting the Child with Reflux. The four sessions cover diagnosis, treatment and coping in an informal discussion based format. By the end of the year, PAGER is hoping to conduct GERD 101 classes in six states and keep expanding as staffing allows.

(Continued on page 5)

The Pediatric Adolescent Gastroesophageal Reflux Association By Jan Burns, PAGER

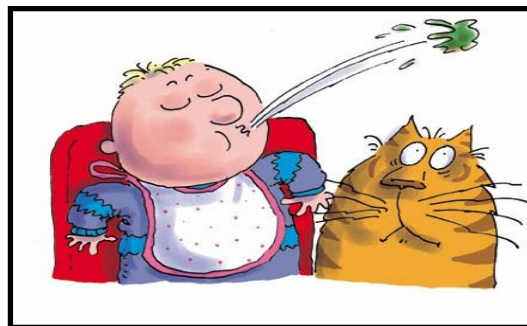
Every spring, PAGER Association participates in a lobby effort at the US Capitol with the Digestive Diseases National Coalition. This year, PAGER was instrumental in leading an effort to lobby for legislation mandating insurance coverage for medical foods such as formula other liquid nutrition. Many children with GER need prescription formula due to allergies, tube feeding or intolerances, leading to astronomical bills.

Over the years, families reported to PAGER that other members of their family (siblings, parents, grandparents, etc) all had reflux. Eventually PAGER was able to convince a group of researchers to study this and in 2000 they found the region of Chromosome 13 that contains a gene for genetic reflux. It is believed that there may be several types of reflux (allergic, protein intolerant, autonomic instability etc) and much more research is needed. PAGER Association believes more research is needed to study prevalence; treatments, sequelae and caretaker burden and is interested in collaborating with researchers on issues related to GER.

While it is believed that reflux affects approximately 5-8% of children (mirroring the prevalence of adult reflux), it is clear that reflux affects infants and children with developmental disabilities in much higher proportions. Several studies have documented an incidence ranging from 50-80% for children with autism, prematurity, cerebral palsy and Down syndrome and many other genetic conditions. A child with neurological/developmental problems may appear to be irritable and unmanageable if the pain and discomfort of GER hasn't been addressed. PAGER has heard some real happy endings to sad stories when young children who are unable to communicate their needs suddenly start to respond to their environment and develop when aggressive, appropriate treatment for GER was instituted and their excruciating pain relieved. It is vitally important for intervention staff to address the underlying pain/discomfort of reflux by sending a child to the medical team for management prior to beginning a structured feeding protocol.

PAGER Association supports parents, guides them to resources and gives them the information needed to make informed decisions regarding the care and treatment of a child with reflux.

PAGER Association P.O. Box 486
Buckeystown, Maryland 21717
www.reflux.org 301-601-9541



Questions and Answer: From the TelAbility website – www.TelAbility.org

My daughter has problems aspirating her secretions and it's hard to brush her teeth without her strangling. Do you know of any toothbrushes or equipment that could help?

Joshua Alexander, MD: Ask your dentist about using a Plak Vak. It's a toothbrush that attaches to a portable suction machine. At http://www.trademarkmedical.com/personal_use/plakvac.html you can find more information about this product and order a demonstration video.

Case by Case...: An older child with food refusal

by Jenn Rayburn, MS SLP/CCC, UNC Hospitals, Chapel Hill, NC

SD was a typically developing 7-year-old boy seen at UNC Hospitals for an oral motor, feeding and swallowing evaluation. His mother's primary concern was SD's extreme food selectivity and hypersensitive gag.

Medical History:

Pulmonary: SD presented with asthma like symptoms including wheezing and frequent upper respiratory infections. He had 2 cases of pneumonia and 7 cases of bronchitis over the last few years. He experienced coughing overnight and congestion every morning. He took Albuterol, Advair and Singular to help manage his respiratory symptoms.

ENT History:

SD had a history of sinus infections, nasal congestion, ear infections and seasonal allergies. He took Zyrtec and Rhinocort to manage these symptoms.

GI: SD and his family had a history of a gastroesophageal reflux (GER). SD spit up frequently as an infant and often seemed uncomfortable. He had difficulty transitioning to baby food and solids and was described as a picky eater. At age 2 his food selectivity became more pronounced. He presented with the following signs of GER from age 2 to age 7: frequent burping and hiccups, gagging, daily stomach pain, grimacing with swallowing, bad breath, throat clearing, self limiting food intake, hoarse voice, food refusal, and restless sleep. At age 6, a doctor finally took SD's symptoms seriously and put him on 10 mg Prilosec once a day. No improvements were observed. His Prilosec dose was increased to 10 mg twice a day. The only improvements were decreased hiccups and SD finally slept well through the night.

SD also had a history of constipation. At the time of his feeding evaluation, he had a bowel movement once every two days. Passing stool was often painful and caused him to cry. Miralax and other constipation treatments had helped very little.

SD's diet consisted of milk, toast, biscuits, granola, cereal, and chicken nuggets from a specific restaurant. He ate no vegetables or fruits but did take a daily multivitamin. He had recently started refusing raisins and peanut butter. When SD was asked why he refused to eat other foods he said his stomach hurt and he was scared but didn't know why.

Previous Intervention:

From 2 – 3 years old SD received oral – sensory therapy by an occupational therapist and a speech therapist. The therapy did not decrease his gag or improve the variety or volume of food consumed. From age 4 - 5 years old, the whole family saw a child psychologist to assist with food selectivity, however there was little to no improvement in p.o. intake.

Oral Motor / Swallow Evaluation:

SD gagged at the sight of applesauce but handled a small bite without difficulty. He demonstrated normal chewing and drinking skills. There were no clinical signs of aspiration or swallowing difficulty.

Recommendations:

1. Referral to pediatric GI clinic for constipation, reflux, abdominal pain, and food allergy work-up.
2. Consider feeding therapy to increase variety of accepted foods, after GI appointment and GI treatment.

GI Work-up:

Upper GI: normal

pH probe: inconclusive

Endoscopy: normal

Food allergy testing: Revealed allergies to oats, corn, rice, potato, barley, and rye. Slight sensitivity to wheat.

Intervention:

(Continued on page 7)

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by Jenn Rayburn, MS SLP/CCC, UNC Hospitals, Chapel Hill, NC

(Continued from page 6)

The family was relieved to find out there was a reason behind his poor eating but were scared about how the food allergies would further limit his diet. SD remained on Prilosec, MiraLax, and eliminated all allergic foods except for wheat. Within one week on his new elimination diet, which consisted mostly of homemade breads, he reported decreased nausea and abdominal pain. Within one month of his elimination diet, he was having regular daily bowel movements without MiraLax or any constipation medicines. Within three months of the elimination diet a decrease in asthma symptoms was reported. He began to eat more of his preferred foods but still was not willing to try new foods.

After three months on the elimination diet, SD's mother decided to try feeding therapy to increase the variety of accepted foods. I had the Mom pick 10 foods for SD to work on. The foods had to be something the family ate regularly for convenience and also something that was safe for SD's elimination diet. The first 10 foods chosen were: blueberries, applesauce, pears, bananas, carrots, green beans, peas, turkey, hotdogs, and chicken. SD chose to work on applesauce first.

Therapy Program: (included consultation from a behavioral psychologist specializing in feeding disorders)

Taking bites of new foods was too challenging for SD, so we started with touching food to increase his exposure and comfort level with each food. Touching food made therapy easy and successful for him in the beginning. All of the touching food sessions were conducted outside of mealtime.

SD had to touch the applesauce 5 times everyday for 1 week. His mother kept a daily / weekly log and SD put a sticker on the chart each time he completed his 5 touches for the day. At the end of the week, with 7 stickers on the chart, he got one dollar to spend at the dollar store. Each week one food of SD's choice was added to therapy. The new food was introduced in therapy and then continued daily at home. This continued until he was up to touching 4 foods, 5 times, everyday for a week, for one dollar. After 4 weeks of touching applesauce everyday we felt SD was ready to begin tasting. SD began tasting foods the same way he began touching them; 5 times a day, everyday for a week, earning him one dollar for the dollar store. Tasting lead to normal sized bites and his comfort with bites lead to less need for reinforcement. New foods were started into the touching rotation and successful bites of food were moved into mealtime. Two months into the program he was able to go straight to tasting with some new foods and others he still needed to start with touching. We allowed him to make the decision. He was able to earn one dollar/week for those foods he was touching and one dollar/week for tasting or biting foods.

SD became proud of the new foods he was able to tolerate. He enjoyed bringing in his toy from the dollar store each week to show me what he had earned. His success with blueberries led to acceptance of blueberry muffins and blueberry pancakes and his diet continued to expand. Occasionally there was a food that was just too challenging so we allowed him to pick another new food to work on in its place. His mother became comfortable with the program and therapy was reduced to every other week and then once a month. After 4-6 months his diet had expanded to 35+ foods including: pears, bananas, apples, peaches, meatloaf, meatballs, cheeseburger, pineapple, bacon, pork chops, soy nuts, spelt flake cereal, and pizza.

Conclusion:

I believe this program was successful for several reasons. First and most importantly, the underlying reasons for SD's food refusal (food allergies / GI discomfort) were identified and treated before therapy began. He also had a family who was committed to working on the program at home on a regular basis. SD had input into many of the decisions made during his treatment, which gave him a sense of control. Therapy was successful and positive for SD in the beginning by starting with touching food instead of eating it. The use of daily stickers gave him an immediate reward and the weekly reward gave him something to work towards. Today, almost a year later, SD no longer needs reinforcement to eat or try new foods. He has a varied diet including meats, vegetables, fruits, dairy and breads.

Supporting Hydration during Tube -Wean

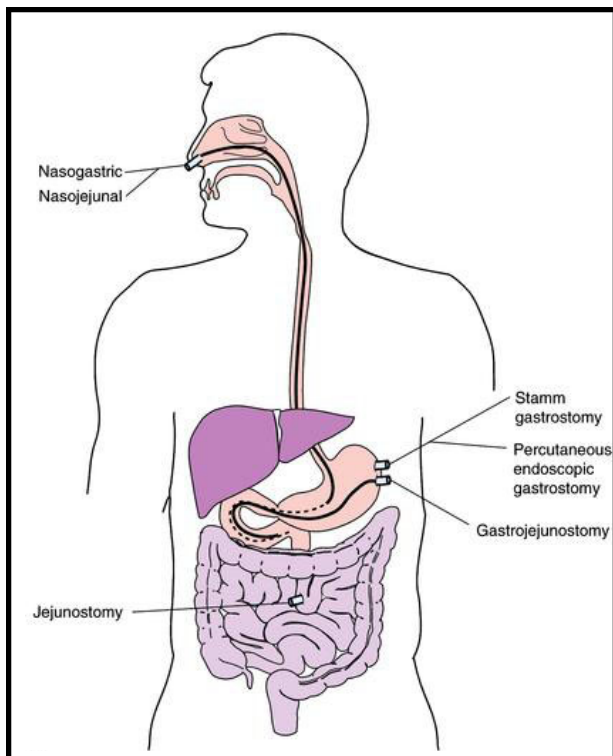
By Kyra Hill, M.S., CCC/SLP, Encouragement Feeding Program, University of Virginia

When considering weaning a child from tube feedings there are many variables that impact success. Hydration is especially important when planning to decrease or eliminate tube-dependence. There are numerous tube-weaning protocols with varying approaches but all should factor in fluid intake in order to optimize the digestion and absorption of nutrients, and the elimination process.

Initial assessment of a child's current hydration status should be conducted beginning with comparison of a child's present fluid intake to their estimated fluid needs. A thorough assessment should also evaluate the presence of possible signs of mild dehydration such as low energy level, gastric retention, thick mucous/secretions, and constipation. Such gastrointestinal complications are common barriers to oral feeding advancement in tube-dependent children. Because mild dehydration can also be asymptomatic and thirst is especially unreliable in children (especially if they have special health care needs), guidelines have been established that remove much of the guesswork from figuring out how much fluid a child needs.

There are a variety of recommendations regarding the determination of fluid needs in dietetic and pediatric literature ranging from broad to highly individualized. According to Food, Nutrition, and Diet Therapy (Mahan & Escott-Stump, 2000) daily fluid needs can be reasonably met with 35 mL/kg for adults, 50-60 mL/kg for children, and 150 mL/kg in infants. However estimating needs based on weight is more reliable, especially for children who do not follow typical growth patterns. The AAP recommends the following minimum requirements: (Shelov, S, (1998) Caring for your Baby and Young Child. Bantam: New York; pp. 491.)

6-7 lbs	10oz	26 lbs	28oz
11 lbs	15oz	33 lbs	32oz
22 lbs	25oz	40 lbs	38 oz



A more specific is the Holliday-Segar Method. The Manual of Clinical Dietetics also recommends this method of determining basic hydration needs for children over 2 months. Therapists should limit use of this method for provision of a baseline for daily fluid requirements. Unlike the using a caloric Method it does not account for various types of water loss. Children with a history of malnutrition or other medical complications should be followed closely by a dietician for ongoing assessment of their nutritional status. *Children who have fluid restrictions related to a medical condition may not be appropriate candidates for rapid tube weaning protocols.

Holliday-Segar Fluid Calculation Method (Pediatrics Vol 102, No2, Aug 1998 pp.399)

<u>Weight</u>	<u>Fluid Needs</u>
1-10 kg	100 ml/kg/day
11-20 kg	1000 ml/kg/day + 50 ml/kg >10 kg
>20kg	1500 ml +20 ml/kg >20kg

Illustration: www.gastroatlas.com

(Continued on page 9)

Supporting Hydration during Tube -Wean

By Kyra Hill, M.S., CCC/SLP, Encouragement Feeding Program
University of Virginia

(Continued from page 8)

Example:

Admit weight= 11.4 kg

Admit fluids= 450cc formula via tube; 90cc water PO;

120cc puree PO = 22 oz/day

=1000 ml + 50 ml x 1.4

=1000 ml + 70 ml

=1077 ml/day

1077cc divided by 30cc/ounce = 36 oz/day

Fluid adjustment= + 14oz/day



The initial goal should be to optimize hydration levels seen during the pre-tube feeding weaning process. Free water (hospital term for extra water) should be used for improving hydration via tube when caloric needs are being met. Adding extra formula, juices, or blended diet to increase hydration can easily lead to overfeeding with resultant emesis and decreased desire to feed orally and obesity. Fluids should be added throughout the day according to volume toleration of the individual child. Water can either be administered independently of formula administration or 30 to 45 minutes prior to a tube feed to avoid difficulty with poor toleration of large boluses. As oral fluid intake increases, water via tube should be decreased accordingly. (It is important to remember fluids include pureed and strained foods in addition to all liquids.) In uncomplicated cases in which a tube is being maintained for hydration purposes only, 75% of calculated fluid needs accepted orally with good urine output and regular stooling may be adequate for a trial of discontinuing hydration via the tube.

As feeding therapists we should always consider a child's hydration status and provide parents with the information they need to support adequate fluid intake on a daily basis. Establishing and maintaining good hydration using appropriate fluids may well be one of the most important considerations for successful tube weaning and long-term good health.

Reviewed by Sharon Wallace, RD, CSP, CNSD, LDN

On the Research Front:

Redstone, F. West, J.F. The importance of postural control for feeding. *Pediatric Nursing*. March-April, 2004, vol. 30, no.2.

Correct postural alignment is important in the normal feeding/swallowing process. Effective oral function for feeding begins with pelvic stability, trunk alignment, and head and jaw control. Children with neuromotor abnormalities often have decreased postural control that exacerbates feeding and swallowing problems. Techniques such as therapeutic seating and oral control can enhance postural alignment and improve oral functioning for the safe intake of food.

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Hiro Publishing
607-B North Greensboro Street
Carrboro, NC 27510
www.feedingnews.com
one: 919-967-2070
Fax: 919-843-3280
Email: Kbracket@mail.unch.unc.edu

Special for Feeding Therapists and Professionals!

Questions, comments, submissions, and suggestions are all welcome. Please be vocal, the hope is that this forum will be educational and will help to connect us as professionals working together.



On the Research Front:

Hendy, H. M. Effectiveness of trained peer models to encourage food acceptance in pre-school children. *Appetite*, 2002, 39, 217-225.

This study looked at the effectiveness of trained peer models to encourage food acceptance in children during preschool meals, and one month later. Results indicated that the effectiveness of trained peer models does not last beyond the modeled meal.

Fung, C., Khong, P., To, R., Goh, W., and Wong, V. Video-fluoroscopic study of swallowing in children with neurodevelopmental disorders. *Pediatrics International*, 2004, 46, 26-30.

This study looked at the role of the VFSS in assessment and management of 4 children with neurodevelopmental disorders in a feeding team. The team approach is described. VFSS aids in assessing the type of swallowing problems and formulation of treatment goals.



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