Kids with Tubes News

A newsletter connecting parents and caregivers of tube-fed children

Letter from the Editors

For the tube-fed child, the conditions that warranted placing the tube, along with the side effects of it, often require intervention by one sort of therapist or another. It can be overwhelming to hear the services that professionals recommend, and it can be confusing when trying to understand what the therapy has to offer. This issue of *Kids with Tubes News* provides practical overviews of therapies typical for the tube-fed child.

The therapies covered within this issue include Sensory Integration, Oral Motor/Oral Sensory, Speech and Language, Physical Therapy, Group and Individual Feeding. Professional therapists having extensive experience with tube-fed children have written each of these overviews with our children in mind. Coupled with several articles are contributions from families describing how they have benefited from the given therapy and, where appropriate, how they have incorporated it into their home routine.

We think you will want to read this newsletter over a period of time. It is dense in content. You may be learning about these therapies for the first time. Or you may already be involved with them for your child. For the former group, we think you will want to use this issue as a reference guide to what is available and how it could apply to your individual child. For the latter group, this newsletter may give you a deeper understanding of the treatments your therapists are offering, and therefore a better basis for communication.

Because the underlying conditions and oral potential of our children is so wide ranging, you should remember that not all of these therapies will apply to your child. Furthermore, many of the therapies included here may not even be available in your geographic area. Nevertheless, we hope the information in this issue will enrich your understanding of your child and his or her treatment needs.

As parents it is impossible to ignore how mind-boggling the therapies can seem. We often get several suggestions from each of the multiple therapists involved with our child. We may be given many suggestions for things to "try at home". There are lots of good ideas. Trying to "do it all" can leave us feeling defeated and inadequate. That is NOT the intention of this newsletter. Instead, we recognize that each of us is applying the therapies in a way that fits into the greater picture of our family life, as best we can, at any point in time.

We thank Patty Donnellan, Gretchen Finchum, Patricia Huntley, Deirdre Mulcahy Patch, Priscilla Osborne and Christine Yannone for their articles in this newsletter. We also thank the families who contributed their personal experiences.

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Spring 2001

Therapies for the Tube-fed Child

Our shared principles:

- *Each child with a feeding tube is unique – what works for one child and family may not work for another.*
- *Always check with your child's doctor(s) and/or therapist(s) before using any information presented in this newsletter for your child's treatment or care.*
- *All information that is learned through any Kids with Tubes forum is to be treated with complete respect and confidentiality.*
- *Some children will outgrow the need for a feeding tube, others will have a tube for their lifetime; we seek to support all parents and caregivers of tube-fed children, whatever their experience will be.*

Sensory Integration Therapy

Patty Donnellan, OTR/L

> *I have a hard time explaining my daughter's Sensory Integration diagnosis because I have a hard time understanding it myself. But, the manifestations of SI are obvious in her case. She retches when we rub heavily scented suntan lotion on her body. She vomits when asked to touch shaving cream. And she gags when she watches us put on deodorant or face creams. When we began the brushing therapy that is often included in SI treatment, she gagged when we rubbed the surgical brush on her arms...*

Sensory Integration (S.I.) is the ability of the brain to detect, modulate, discriminate, and integrate the three special sensory systems – tactile (touch), vestibular (movement), and proprioceptive (body awareness). Although these sensory systems are less familiar than the visual (seeing), auditory (hearing), gustatory (taste) and olfactory (smell), they are critical in order for humans to experience, interpret and respond to the various stimuli in our environment.

Tube-fed children are prone to develop S.I. dysfunction or difficulties. This may be a result of the fragile medical conditions which warranted the tube placement, their premature nervous systems or their lack of early sensory input. Sensory integration dysfunction in children causes them to process sensory stimuli from the environment (i.e. sights, sounds, touch, tastes, smells, and movement) in an inaccurate way, resulting in "sensory seeking" or "sensory avoiding" behaviors, or "dyspraxia."

Children who have "*sensory seeking*" behavior are commonly children with nervous systems that are *under-responsive to sensation* (hypo-sensitive). They do not always process sensory information that is coming into the brain.They may seek intense sensory experiences for an extended duration. They may demonstrate any or all of the following behaviors:

- Hyper-activity, impulsivity, decreased response to pain
- Poor body awareness - clumsiness, touching objects or others too hard or too often
- Love for foods that are spicy, hard/crunchy, extremely cold/hot in temperature, carbonated drinks, and over-stuffing their mouth of food

Children who have sensory avoidant behavior or "*sensory defensiveness*" are commonly children with nervous systems that are *overly responsive to sensation* (hyper-sensitive). They may have "fight or flight" responses to sensory stimuli. They may demonstrate any or all of the following behaviors:

- Responding to being touched with withdrawal or aggression (Tactile Defensiveness)
- Unwilling to take risks, extremely cautious in their environment (e.g. playgrounds)
- Motion sickness, afraid of heights (e.g. carsickness, refuses to get on a slide)
- Anxious/uncomfortable in over-stimulating environments (e.g. malls, playgrounds, public transportation)
- Very picky eater – refuses to eat certain textured foods, sensitive to some food smells or temperatures (Oral Defensiveness)
- Avoiding touch with substances (e.g. messy foods, mud, sand) or will only use utensils or fingertips rather than whole hand to manipulate objects
- Struggles with self-care activities; will only wear certain types of material for clothing and or wear clothing in a particular way (e.g. socks, no hats); complains with face washing, hair brushing, tooth brushing, and hair cutting.

Children who have "*dyspraxia*" have poor motor coordination as a result of decreased proprioceptive (body awareness) and/or vestibular (movement) processing of the central nervous system. A child with dyspraxia may be a very clumsy child or a child who has much difficulty coordinating the tongue for movement when formulating words or managing foods.

It is important to note that a number of medical conditions can also interfere with efficient and effective sensory processing. Examples include gastro-esophageal reflux, low muscle tone, side effects to certain medications and visual impairment. For example, a child with low muscle tone in the body or mouth requires an intense amount of sensory input in order to facilitate a muscular response. Some medications can affect the sense of taste or cause nausea, which may cause a child to react to a mealtime experience in an overly sensitive manner. Or, a child with a visual or auditory impairment may have a startle response to food entering if they are not warned that food is about to enter the mouth or is not permitted to explore the food beforehand. A choking or gag response may occur in these situations and can be confused with thinking that the child has an oral defensiveness due to sensory integration dysfunction. A child with reflux may experience excessive vomiting resulting in an inflamed throat and mouth, most likely leaving him/her uninterested in eating.

If you suspect that your child may have sensory integration difficulties, it is first suggested that you keep a journal of when these behaviors occurred, where they happened, who was involved, and how your child responded. You then may see a pattern of why these behaviors occurred. The journal will be helpful information when seeking the help of an occupational therapist (O.T.). When seeking the help of a therapist, review with him/her their background and whether they are experienced with sensory integration therapy. Not all O.T.s are formally trained or certified in Sensory Integration Theory.

The goal of S.I. therapy in occupational therapy is to help the child's sensory system adapt to the normal "occupations" of childhood – playing, eating, dressing, washing and sleeping. Treatment helps to improve a child's self-regulation, sensory-motor abilities, social participation and self-esteem. This is accomplished by motivating and guiding the child through challenging activities, helping the child's nervous system make a successful and organized response. Most importantly, occupational therapists strive to provide parents with a clear understanding of S.I. and supply a "sensory diet" - a custom home program designed specifically for their child. The sensory diet provides a number of activities and ideas to help the child on a daily basis at home and in the community. The key to a successful sensory diet is that it is effective in providing the input your child's nervous system needs, it easily fits into a normal routine, and it is fun for both the parent and child. The time frame of treatment is variable according to insurance benefits and your child's needs. As a parent, you should see changes in your child's behavior fairly quickly, if therapy is consistent and the home sensory diet is carried over on a daily basis by caregivers.

Here are some mealtime ideas that may be helpful when working with tube-fed children (eaters and non-eaters) that have sensory issues:

- Let them play with the food as much as possible. Make food fun. If they throw the food, instead have them kiss it or bite it goodbye into an "all done bowl." Always offer the food you are eating for them to explore. Talk about it with them, e.g. "It's soft, hot, green, etc."
- For non-eaters, encourage the child to explore their favorite toys orally. Dip them into flavored water, pureed foods, etc. Help the child be more comfortable with hands/ toys/ foods being in or near their mouth.
- Be observant of the eating environment – Does your child need a distraction such as music? Does your child need a puppet/favorite character to help them model eating? Would it help to place a mirror in front of them to see where their mouth is? Is the seating comfortable and positioning appropriate so that they do not slip out or slump?
- Make eating time a regular routine and make it fun!
- Before eating: Do the Wilbarger brush therapy/joint compressions as well as an oral stimulation warm-up (e.g. NUK brush, toothbrush, massager, fingers, washcloth).
- During eating: Do not present all foods at once. Instead, present them one at a time. When your child gestures or says that they are all done with that food, clear all of it away from the table, hands and mouth with a wash cloth before going onto the next food.
- It is helpful to make a picture book that tells a story using their personal photos doing oral exercises of "How to warm up your mouth before eating." Make it a routine to use this book before mealtimes.
- After eating, praise the child for whatever success they had. If there was none, always be positive and say, "Nice trying!"
- On a regular basis, perform massage (for example the Rice Infant Sensory Stimulation (RISS)).

To learn more about Sensory Integration, see the Reference Section on page 15 of this newsletter. ❑

Our son was born gigantic. At 10 lbs. 3 oz. people laughed when I said he didn't eat. Everyone was incredulous when he was hospitalized at 3 weeks old for Failure to Thrive. We went to all kinds of professionals and they all said, "He needs to eat more." "He needs to gain weight." But no one said how to make this happen, and no one was overly concerned because he was "good sized", "tall but thin" and "what most people aspire to be."

After many examinations and tests, I was told he had severe reflux, aversions to textures and smells, and learned negative behaviors towards eating. Because I am a special education teacher, I knew a bit about aversions, behaviors and sensory integration. I went to the occupational therapist in my building and got the first real "help" for the problem.

It was suggested that I start an oral desensitization program starting with gum massage and some "deep" (you can only go so deep in the mouth) pressure. She said this would not only make him less sensitive but would alert him that food was coming so it wasn't a surprise. She suggested doing the gum massage with my finger and Pixie Stick (flavored sugar). This would give a texture, a distinct sweetness for alerting, and an enjoyable taste so he would start associating eating with something enjoyable. After the massage I would dip a NUK brush in Pixie Stick and press on the roof of his mouth, tongue and inside his cheeks with my hand on the outside. This gave stimulation and pressure. Finally, we used a Dum Dum lollipop (small round pop) to practice sticking out his tongue and give a little more pressure. After that, he could keep the lollipop and eat it while I got the food ready. We did this twice a day. (It would have been 3 times a day, but I don't feed him lunch weekdays because I am working)

It made a difference almost immediately. First, I felt like I was actually doing something to help, and more importantly he enjoyed having something edible in his mouth and didn't cry or throw up. We continued this for several months until he moved to the "next level" of treatment. This to me was the most significant assistance we had gotten in my son's short 8-month life. These techniques and the occupational therapist's suggestion to request Early Intervention services made all the difference.

Oral-Motor/Oral-Sensory Therapy

Christine Yannone, M.S., CCC/SLP

The development of our oral structures and their functions is a complex process. Mastery of oral abilities allows us to eat and drink a variety of foods and liquids as well as produce the necessary sound sequences to create words and sentences. Oral development involves acquiring skills that are movement-based as well as sensory-based.

For example, to produce the /d/ sound, one must elevate the tongue tip to touch the roof of the mouth right behind the teeth and to then coordinate a 'flick' of the tongue up against the roof of the mouth while concurrently moving the lips, teeth, cheeks, and vocal cords. This split second process of coordination requires both motor skills (the strength to move the tongue) and sensory processing abilities (awareness and timing of tongue placement). Preparing food to swallow requires very similar motor and sensory abilities. Children develop these skills through repeated oral experiences starting at birth. Such experiences include, but are not limited to, mouthing a variety of objects, babbling, sucking, eating, and making sounds such as "raspberries".

For the child who requires tube feedings, these oral experiences can be disrupted or non-existent. Due to medical complications, tube-fed children often experience invasive and/or painful oral procedures. These procedures often interfere with normal oral sensory-motor development. Structural abnormalities (e.g. cleft palate) and neurological immaturity or abnormalities may also result in an aversion to typical oral experience. Often a series of negative oral experiences, not an isolated incident, alters the course of normal development. This article will briefly review assessment of oral-motor abilities and will then describe the therapeutic process to address oral sensory-motor issues.

Typical oral-motor development occurs in a predictable progressive pattern. Both strength and coordination must be achieved in order to master oral efficiency in both speech and feeding abilities. Speech and feeding skills typically develop concurrently. There is obvious overlap in the oral structures involved in both of these areas. However, there is controversy about the interconnected nature of skill acquisition for feeding and speech. For each of these areas, there is a successive pattern of typical development that leads to skill mastery. These typical patterns of development guide the assessment and therapeutic processes.

Assessment

When evaluating oral-motor abilities, the appearance and movement of the oral structures are assessed. *Oral structures* include the jaw, tongue, lips, teeth, palate, cheeks, and throat. The shape, size, color, and growth are observed. Differences in development are noted which may effect oral-motor abilities. In addition to the structures, the adequacy of *oral functioning* is evaluated by watching how the structures move. A clinician engages the child in a variety of oral activities that may include speaking, eating, imitating, mirror play, bubbles, whistles, and/or singing. The quality of movement is evaluated by observing the rhythm, stability, efficiency and separation of oral movements. In addition, *muscle tone and sensory processing* are observed. If any of these characteristics appear to impact the child's ability to speak and/or eat, oral sensory-motor therapy may be recommended.

All speech pathologists are trained to evaluate oral structures and their function for the purpose of speech production. However, only some speech pathologists and only some occupational therapists are trained to assess and treat oral structures and their function as it relates to feeding. In choosing a clinician, it is important to inquire about these qualifications.

Treatment

When a child begins oral-motor therapy, a therapist will often engage the child in an activity that stimulates the whole body to prepare the child for the more challenging oral-motor work. This may involve bouncing, swinging, jumping, etc. The whole body stimulation facilitates a calm and awake state. This is similar to what people experience through exercise. In exercising, we ready our bodies to deal with the stresses of daily living by physically preparing our body to cope with stressful situations. Whole body stimulation seeks to prepare the child for optimal learning during challenging oral activities by facilitating a relaxed and alert state.

The purpose of oral sensory-motor therapy is to establish appropriate oral experiences related to feeding and/or speech. Therapy is broken down into a number of goals, some of which may be worked on simultaneously. *One of the first goals of therapy is to increase the child's awareness of oral structures and how they work.* This is accomplished by educating the child about their oral structures. While stimulating the structures with fingers, mouth brushes, or toys the adult labels the place of activity for the child; "I'm touching your lips." Labeling can be incorporated into a wide variety of activities such as making silly faces in the mirror, singing a song with each verse focusing on a part of the mouth, washing the face and brushing the teeth, or imitative games.

Another initial goal may be to normalize the child's oral tactile sensitivity. This means teaching the child to tolerate touching both on the face and in the mouth with a variety of textures (bumpy, smooth, soft, hard, etc.) and temperatures. This is done by gradually providing the child with appropriate sensory experiences. These experiences may include mouthing of toys, oral massage, vibration, mouth brushing, face washing, and whistle and bubble blowing. The combination of activities is dependent upon the child's specific needs. Some children are very sensitive (hyper-sensitive) to oral touch, while others lack in sensitivity (hypo-sensitive). The goal is for the child to be both aware of sensation and tolerant of a variety of sensations.

Normalizing sensitivity also includes facilitation of an appropriate gag reflex. When an infant is born, they will gag when varied textures are introduced into the mouth. This is a protective response that is designed to prevent choking. Typically, the gag reflex is fully 'integrated' by approximately 24 months of age. This means that the sensitive spot that triggers a gag moves to the back of the throat. This movement allows children to develop the ability to eat a wide variety of food textures. (Most of us have a gag reflex that can be triggered by touching the back of the throat with an object.) Often times, children who have developed oral sensory-motor difficulties will continue to have a forward gag reflex or an over-sensitive gag reflex. For these children, gradual, guided oral sensory-motor experiences are utilized to facilitate gag integration.

Oral stimulation activities can be modified to meet the child's level of development. For example, rattles may be used for mouthing for a toddler while popular figurines might be used for an older school age child. While engaged in an oral activity, the adult describes the characteristics of the experiences. These activities can often be overwhelming for children. It is important to move slowly as well as to provide the child with safe models of how they might engage in the activity. For example, while mouthing a NUK brush the adult says, "Oh, this brush feels bumpy. I can lick it with my tongue. You can lick it with your tongue too."

An important part of oral-motor development involves coordination of the oral structures and their separate and precise oral movements. This allows for mature feeding patterns and speech sounds to develop. To accomplish this, therapy addresses oral muscle strength as well as differentiation of oral movements. Differentiation means that the movement of oral structures occurs independent of one another. By providing the child with repetitive oral-motor experiences based upon the normal sequence of development for eating and/or speech, strength and differentiation are facilitated. Goals are picked according to the child's current level of functioning and the next developmental step. Goals are accomplished through typical oral activities. For example if lip strength were a goal, activities might include: lip smacking, smiling, puckering, blowing kisses, blowing bubbles, using a straw, raspberry noises, etc. These activities can all be modified to fit the child's level of interest and age.

As a tube-fed child often has a history of adverse oral experiences and may have developed atypical oral-motor survival strategies, it is sometimes necessary to eliminate abnormal oral movement patterns and replace them with more normal patterns of movement. This involves assessing the whole body as it performs oral-motor tasks. Initially, therapists may need to focus on body positioning in order to provide the child with a stable base from which to initiate oral movement. For example, it is really difficult to coordinate breathing and jaw movements when seated in a slouched, hunched over position. Aligning the pelvis, spine, and head allows the chest and jaw to move more easily and efficiently. Abnormal patterns are often learned coping strategies, and therefore, they can be difficult to change. Although initially more difficult, it is important to promote practice of the correct movement in order to facilitate long term positive effects.

Oral-motor development is a complex process that involves the whole body and sensory systems. It is an important foundation for both speech and feeding skills. In addition to therapeutic sessions, oral sensory-motor therapy should include a home program. Repetitive, reinforcing oral experiences in a variety of environments will facilitate long-term positive effects. The most beneficial therapeutic program incorporates the child and parent in the process. ❑

Our son had a special box with just oral motor toys that we would pull out once a day for "special play". Inside the box were bubbles, whistles, textured teethers and rattles, a "buzzer bug" (vibrating ladybug), toothbrush with a bell in the handle. It also included Pixie Sticks which we poured onto a mirror for him to kiss and lick off.

We made it an occasion to take out the box so that he would feel this was a special playtime and enjoy the activities. We would go through as many of the activities as he could tolerate. We would sing songs to coincide with different toys and make it fun and upbeat. We also brought out the Old MacDonald book at this time, singing each of the pages to make it more fun. We changed and added toys frequently to help make it interesting.

Speech Therapy

Gretchen Finchum, M.S., CCC/SLP

A child that is learning to express and understand their needs and feelings is a child that is learning how to define who they are and how they can communicate in their world. Interference in the intricate progression of early communication certainly factors into many of the processes of later learning. For the tube-fed child, extra guidance such as family focused speech language treatment is essential in building the tools necessary to address challenges in feeding and communicating.

Tube-fed children may need the services of a speech language pathologist (SLP) along the way. The SLP will work with a team of professionals and could be the primary feeding therapist or could work in conjunction with a feeding specialist. Speech-language treatment (SLTx) for tube-fed children may include any of the following areas of development: verbal and non-verbal expressive language, receptive language, oral motor, and auditory and phonological development. Other areas, which may be addressed, include pragmatic development, behavior, social emotional and alternative/augmentative means of communication.

Receiving feedings by tube may not be the sole reason that SLTx is warranted. Tube-fed children may have a variety of other diagnoses affecting Sp-Lang development including prematurity, neurological impairment, physiological or anatomical differences. In addition, the SLP's treatment of tube-fed kids may overlap to a great degree with the occupational therapist in the areas of sensory and motor abilities as well as self-feeding.

Before highlighting the indications, goals and strategies for SLTx it is important to briefly touch on the controversial issue of the relationship between the development of oral-feeding skills and the development of oral-speech skills. Researchers have argued that feeding and speech follow two different developmental pathways, yet clinician and parent experiences suggest the two skills are very closely related. For example, there are parallels between the motor movements needed to eat and those movements and processes (i.e. oral-motor, respiration, postural positioning, head control, and cognitive and receptive language skills) needed for speech sounds. While there is neither an automatic transfer of skills nor a clear cause and effect relationship between feeding and speech development, the clinical importance of the relationship between these skills should not be overlooked.

- A tube-fed child needs repetitive oral and sensorimotor experiences (whether they are eaters or non-eaters).

- A tube-fed child needs help to learn the connections between these two major oral systems. This is especially true for the non-eating tube-fed child.

Learning the connection is key and must be shown to the child by sensory exploration, facilitating sound play and a strong focus on oral motor skills. In general, the tube-fed child will learn the major motor movements for making sounds before generalizing those movements to skillfully managing food. However, for the non-eater, clinical experience has shown that speech and language skills do indeed develop without having food oriented experiences during which to practice the motor movements.

Indications for SLTx may occur at any stage of development and treatment may continue as long as necessary. The following sections describe the indications, target goals, and possible strategies for SLTx for tube-fed children ranging in age from infancy to school age.

SLTx for the tube-fed infant:

Indications:

- Delayed babbling – no production of repetitive consonant vowel (CV) syllables or limited variety of consonant sounds
- Delayed production of alternating CV syllables in babbling - difficulty moving from sound to sound (ba-da-mi)
- Excessive drooling and/or open mouthed posture- early indicator of possible motor planning, sensory issues or poor trunk control
- Difficulties with imitation of gestures, and speech and non-speech sounds (e.g. "raspberries", tongue clicking)

Goals:

- Increase sensory awareness of early speech sounds through helping the child feel their tongue, lips, cheeks during movement, touch, massage, sound play
- Increase vocal sound play through imitation
- Facilitate joint attention and reference (eye contact, shared attention to people and objects)- key aspect of a baby's early understanding of what communication is all about
- Increase non-verbal ways (facial expressions, body language, gestures) to express intention (saying hello, requesting, labeling, protesting)

Strategies:

- ORAL MOTOR – ORAL MOTOR!! - stimulating oral motor and sensorimotor skills beginning at an early age and continuing through a therapy program is of paramount importance and cannot be stressed enough. For the sake of delineating treatment approaches, oral motor strategies will not be discussed here. Please see related article on Page 4 of this newsletter.

- Mirror play – make silly noise, faces and body movements
- Imitate vocal attempts made by the baby whether they are speech or non-speech sounds (e.g. gurgling or raspberries)
- Play with sounds that can be shaped into early word approximations – e. g. working on bilabials /b/p/m/ may help lead to key first words, mama, bye-bye or papa
- Incorporate singing and music into daily play activities (bath time, playtime, dressing)
- Pair movement with sounds – give the baby as many simultaneous modalities to learn from as possible (visual, tactile, auditory) – be animated, make a toy cow jump into the air and onto the baby's tummy while saying "moooo" playfully.

When my son was evaluated by the Early Intervention Team he was 11 months old. The speech and language pathologist told us he could not track with his tongue, did not have the strength to pull food off the spoon or chew effectively, and couldn't stick out his tongue appropriately. These were the things he needed to do to eat. My son's speech therapist worked with us to make a "chewing box" filled with different textures to practice chewing (from old, clean sneakers to rattles and chew toys) and gain strength. She had us put some Pixie Stick sugar on his lips so he would practice sticking out his tongue and moving it. She had us make a box of blow toys and bubble toys to use in order to gain strength and mobility in his lips. She also showed us ways to feed him so he could learn to pull food off the spoon with his lips. All of these things we did on a daily basis.

SLTx for the tube-fed preschooler:

Indications:

- Delayed first words and multi-word utterances
- Limited vocabulary of names of people, actions and objects
- Difficulties with articulation / intelligibility – imprecise & highly variable speech production (e.g. omitting final sounds of words, substituting sounds)
- Delayed phonological (sound) development - Is child gaining more complex sounds (sh/f/z) and sound combinations (/str/ fr/)?

Goals:

- Increase use of single words and multiple word utterances
- Enrich vocabulary development for both understanding and expression
- Increase understanding of more complex language – e.g. questions, directions, adjectives
- Help build a variety of sounds in words, phrases and sentences
- Introduce total communication in a more structured way through use of gestures, signs and pictures (photos & symbols) to offer the child any means of communicating possible

Strategies:

- ORAL MOTOR - ORAL MOTOR!! again do not forget the importance of activities such as blowing (bubbles, horns), sensory activities, massage, vibro-tactile stimulation
- Target specific sounds that correlate to movements needed in feeding – sounds /b/p/m/ relate to use of two lips in feeding - sounds like /s/ relate to tone and movement of the tongue
- Use of puppets/pretend food/spoons/ cups in playful games without the pressures of mealtime
- Teach signs for words to make communication easier and to help cue correct sounds
- Use other visual and tactile hand cues to signify specific consonants (e.g. hold an open hand in front of your mouth to signify a /p/ and to feel the breath or have child feel your throat, lips when voicing sounds)
- Read books targeting vocabulary and speech *sounds* (animal noises)

SLTx for the tube-fed school age child:

Many of the indicators highlighted for preschoolers may carry over into later Sp-Lang development.

Indications:

- Continued difficulty with specific speech sounds with slowness of speech and poor intelligibility
- Continued difficulty with motor planning (including developmental dyspraxia)
- Delayed language expression (grammatical forms, length of utterance)
- Delayed language understanding (vocabulary, questions, problem solving, reasoning)
- Continued need to develop/use alternative augmentative language forms (computers, switches, assistive devices, signs, picture/ symbol books)

Goals & Strategies:

- Use of tactile and visual cues to teach and cue specific sounds to target articulation and intelligibility
- Read books, tell stories, describe picture sequences to target vocabulary enrichment and specific receptive language skills
- Continue focus on sensory issues and utilize group situations in the classroom to work on feeding, language and social skills simultaneously (snack time, cooking activities)
- Development of alternative/ augmentative methods such as speech books, communication boards, and training with specialized computer equipment and sign language.

No matter what a therapeutic plan consists of, ultimately the success of a child's communication program is measured by their abilities to grow as an individual, interact with others and enjoy their ever-increasing capacity as communicators. ❑

Physical Therapy

Priscilla Osborne, PT M.S., PCS

The physical therapist on a team addressing feeding concerns will assess the ability of a child's body to provide a secure foundation for the oral motor functions that are necessary for safe and efficient eating. Stability and coordination of the hips, trunk, shoulders, and neck are associated with refinement of sucking, swallowing, and chewing. Also, there is typically a progression of development that affects posture, movement and oral motor control.

In the usual progression of feeding, an infant begins to take food by sucking. A child's body is usually well supported by the person feeding him or her, in a flexed position, with the arms and hands in towards the chest; the trunk, upper body, neck and head are elevated and slightly flexed forward. Sucking and swallowing are facilitated by a slightly flexed posture. If a child is positioned in a more extended posture, his or her airway is at risk because of its elongated position, and the oral motor structures have a lessened opportunity to function optimally. An extended position of the trunk and neck may add to extension of the lips and tongue, thus interfering with appropriate sucking and swallowing. This creates a situation that puts a child at risk of choking.

As a child matures and moves on to more advanced feeding activities such as taking food off a spoon, the feeding position progresses to a more upright posture, often with a child sitting on his or her own, in a high chair. In order to take food from a spoon safely and efficiently, jaw, lip, tongue and mouth movements must change. More competent trunk control is associated with advanced oral motor movement. Most children are moving toward independent sitting at the same time they progress to taking baby foods from a spoon. As more solid foods are taken, advanced chewing becomes necessary; thus trunk and neck support need to become even more advanced and secure. At this point, a child may now be able to sit alone and may be quite mobile in that sitting position. He or she can differentiate movements of the trunk, such as leaning and turning to reach for an object. A child may also now be using arms and hands for reaching and grasping and playing with a spoon. As the need for advanced oral motor movements becomes greater with solid foods being introduced, it becomes even more important that the muscles that support the oral motor cavity become sophisticated in their movements.

Thus it appears there is a parallel in the development of movement and posture of the trunk and neck, and the development of more sophisticated movement of the mouth for chewing and swallowing. The position of the trunk and neck influence the ability of the oral motor musculature to work effectively. If the trunk and neck are not in a secure upright posture, the risk for choking or aspiration increases. Swallowing is difficult if the neck is in too much flexion or too much extension.

Atypical Development

Children with *increased muscle tone* may have a tendency to move into an extended position of the neck, trunk, and hips. This position is not safe for swallowing. Children with *motor coordination difficulties, low muscle tone* or *weakness* may have difficulty maintaining safe trunk and neck positions for eating effectively. Additionally, the posture of some children with motor coordination issues is influenced by early reflex patterns. Head and neck position influences expression of these patterns; and persistence of these patterns can adversely affect oral motor control. Each of these issues requires special consideration for safely positioning a child for eating. A physical therapist can address these issues through both adaptive and therapeutic interventions.

Adaptive Interventions

For all children, positioning during mealtimes is important. A child should be positioned in an upright sitting position with the feet well supported, the trunk as close to upright as possible without compromising a child's head position, and the head in midline and upright. Children without significant motor coordination issues can achieve this position in a typical high chair.

Children with reduced motor control may need additional supports to achieve an optimal eating position. It may be necessary to provide external trunk support to achieve optimal positioning for the development of oral motor control. This can be done adaptively by modifying a high chair, providing a more supportive seat for eating such as an adapted stroller or chair, and/or by providing external support to the trunk through an orthosis or brace. The Soft Spinal Orthosis is an example of a brace used to assist with supporting the trunk for improved neck and head control.

We found an exceptional chair for our son called the Tripp Trapp Chair. It lets him sit at table height AND have his feet supported for mealtime as well as other table activities. It adjusts to fit young children to adults, and it can be modified for special needs.

Therapeutic Interventions

In combination with adaptive strategies, exercises and activities that improve hip, trunk and neck strength and stability should be implemented. The specifics of the program used will depend on the components of motor coordination difficulties that are influencing a child's posture. A program should be individualized for each child, depending on his or her age and specific needs. ❑

Group Therapy

Deirdre Mulcahy Patch, M.S., CCC/SLP

Group therapy is a playgroup routine that provides directed oral sensory motor experiences to support the development of oral feeding skills. Group treatment emphasizes positive exploration and interaction with food. Social reinforcement is provided through peer modeling. The key aspect for group treatment is the group learning environment. Sessions are led by a Speech Language Pathologist and/or Occupational Therapist.

The format of a session varies depending on the provider and the setting. Generally, the format is similar to an Early Intervention program or language group. The format may include:

- **Sensory/motor play**. This involves exploration of sensory and/or motor activities that facilitate a child's organizational state and readiness for learning. This can include, for example, playing in beans or jumping on a trampoline.
- **Circle time**. This is an opportunity for oral-motor practice using familiar songs. For example, singing a "brush your teeth" song with the NUK brush.
- **Snack time**. This involves exploration of food types. Depending on the format, children may bring their own snack or a group snack may be offered. The focus is on emphasizing and rewarding each child's positive interaction with food. Snack time is at least 20 – 40 minutes. This extended time allows for the child to have sufficient warm-up time and opportunity to participate in snack.
- **Parent time**. This is an opportunity for parents to join in a task and discuss treatment activities.

The type of child who may benefit from group therapy includes one who:

- does not like or refuses food.
- has a limited variety of food tastes and textures in his diet.
- is transitioning from tube to oral feeding.
- has difficulty transitioning food textures.
- learns well in a highly structured environment.
- has difficulty with home based treatment.

The criteria for participation can vary from program to program. In general, to fully participate in group treatment, a child must be:

- a minimum of 15 months of age.
- able to learn in a group situation.
- able to attend to simple routine.
- able to follow one-step directions.
- able to attend to others.
- able to imitate simple actions.

Group treatment differs from individual therapy and home-based therapy. It offers a setting that can minimize some of the challenges of individual or home-based treatments, and it provides a positive social mealtime experience.

- It offers a highly structured and predictable routine. Each child's treatment program is individualized. The goal is to change the negative learned behaviors and develop skills to support oral feeding. The predictable routine facilitates participation in "fun" food activities.
- Sessions are up to two hours. Many children with feeding issues need time to "warm-up". The length of the group session allows for this readiness time while still addressing oral motor and feeding skills.
- The group setting emphasizes peer modeling and social reinforcement. In the adult-child interaction, the child knows its time to "perform". The group dynamics facilitate a child's participation and imitation. Children are highly motivated by peers and social reinforcement.
- Group therapy is offered in a clinic setting. The novelty of the clinic setting can facilitate changes in

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Our daughter started group therapy when she was 1 ½ years old. We waited for Spring before we started so as to get over flu season. We were still in fear of having her get sick and end up hospitalized again. Group therapy was her first time being exposed to other children in a group setting. We never sent her to any Early Intervention play groups for fear that she would be exposed to germs. All her services had been provided at home.

She absolutely loved the group. At that point in her life, she desperately needed to interact with other children her own age. The fact that the other kids had similar issues made it all the more comfortable for us. We were amazed at how well she did at group therapy. The NUK brush had always been a reluctant part of her routine at home and with Early Intervention home visits. Group changed her reaction to it within two sessions. It became fun and she learned new songs and saw the other kids using it too.

She was always positioned across from another child who could model for her. Someone with a little more skill at whatever they were doing at the time. This made a huge difference. She was always leery of trying new foods, different textures. Once she saw other kids try it, however, she seemed much more willing to try also.

Group was important also for the parents. It taught us moms a ton of new tricks to get our kids to interact more willingly with food. It gave us a chance to talk among ourselves about various things such as feeding routines, tricks of the trade, the view of the outside world on tube-fed kids. It also gave us the chance to compare doctors, medications, formula, volume, etc. We were able to discuss all kinds of know-how as to what has been tried and what has not worked. If you didn't want to talk about tubes, it was still nice to socialize with other parents.

At some point in our daughter's life, it became evident that a more individual, one on one interaction was needed. It was a real tough decision to leave the group. We were lucky enough to be able to phase out group and have individualized therapy with a wonderful therapist. I think you just know when the time comes for individualized therapy.

Individual Feeding Therapy

Patricia Huntley, M.S., OTR/L

Individual feeding treatment, one child with one therapist, allows a child to learn and practice feeding skills. Alternatively, treatment can be accomplished in a group, allowing a child to see and model the eating of and for peers. Each modality has its own value. Individual treatment and group treatment can occur simultaneously, complimenting one another, or may follow one another.

Before beginning…
Children develop the need for feeding therapy for one of two reasons:
1) He or she was medically fragile and didn't learn (or forgot how) to eat.
2) He or she failed to thrive because of poor sucking, poor eating or picky eating.

First, we'll look at the *medically fragile* child. Oral feeding may not be the highest priority for a child like this, nor should it be. A medically fragile baby will tend to have an immature nervous system, which may later show signs of sensory defensiveness or sensory integration dysfunction. This, in turn, interferes with oral eating. There are, however, some things that can be done to make oral feeding easier for the child when feeding does become appropriate:

- Kangaroo care is very helpful for supporting physiological stability, i.e., regulating body temperature and supporting many other physiological responses.
- Encouraging sucking of hands or pacifiers helps the child to organize as well as to build oral motor strength.
- Encouraging holding of blankets and soft stuffed animals helps the child learn to calm.
- Swaddling is beneficial in helping a baby to organize.

Positive experiences around the face and mouth are extremely important. As the baby becomes stronger, non-nutritive and/or nutritive sucking should be encouraged. This skill is important even if supplemental tube feedings become necessary. Too often, once the tube is placed or shortly thereafter, the child's intake by mouth decreases, sometimes to the point of totally stopping oral eating. It is extremely important to encourage oral feedings as long as they are safe. If it is deemed unsafe for the child to eat by mouth, it still is important to maintain sucking abilities and oral exploration.

Next is the child who has either always been or is becoming a *picky eater*. He or she has gradually eliminated foods, either by volume or variety, and has developed negative responses to eating, e.g. refuses to sit, spits out or gags on foods, cries when meals are presented. At first you may not think too much of it but gradually you become more frustrated. Your child may lose weight or may not gain as recommended. Try to catch the problem before it gets to the point of refusing to eat entirely, as the most difficult condition to overcome is a child who has totally stopped eating.

Have a discussion with your pediatrician if this is a concern. Typically, such children are referred to a gastroenterologist to begin the diagnostic process. The diagnostic process may include various gastrointestinal (GI) tests to rule out medically based feeding disorders. Children may also be referred to a feeding team. Some feeding teams are diagnostic only and may not be able to provide ongoing treatment for your child. Be sure to communicate your desire for ongoing treatment and request a referral for an experienced feeding specialist.

Before beginning individual feeding therapy, it must be determined that:

- *It is safe for the child to feed orally.*

This can be determined by a video swallow study. Children who are not safe to feed orally may still benefit from treatment (occupational, speech, and physical therapy services) to improve oral abilities. As he or she matures, it may become safe for the child to eat. Even if it remains unsafe for the child to feed orally, oral exploration and oral abilities are essential to other developmental skills.

- *Parents must be ready to become involved in the treatment process.*

Feeding is a team effort often involving the therapist, parent, physician, nutritionist and school system (if the child is school age). The most successful outcomes of feeding treatment are when the team works together toward the same goal, at the same speed. It is essential for the parent to be willing to fully participate in the process. Be open and honest with your therapist. Every family has its own unique structure and moves at its own pace. Communicate with your therapist as to what is a comfortable pace for you. If you don't agree or wish not to pursue an area that has been recommended, you must discuss this in order to collaborate and make a plan for the course of treatment. The family's expectations and the therapist's expectations must be similar or the outcome will be compromised. The parent must also be willing to develop a daily routine, spending, at least 10-15 minutes per day addressing feeding. If you are ready to commit to this then you are ready for an intense feeding program.

Ready to begin…
When you're ready to participate in an intense feeding program, seek out a *qualified professional*. The typical course of treatment will involve a par-

ent interview and an assessment of the child's oral motor and eating abilities. At this point a treatment plan will be established. This plan should include your goals as the parent, as well as the therapist's goals based upon his/her knowledge of the feeding process. There also may be recommendations for ancillary services to address other issues, e.g. strength, stability, sensory defensiveness and/or oral motor treatment of underlying conditions related to the feeding disorder. The age of the child will have a lot to do with how the treatment is provided. For the younger child, 0-2 years, treatment may be facilitated by the therapist, yet provided by the parent. Often it will be recommended that these children receive developmental services to address other underlying conditions. The feeding therapist will make suggestions for routine placement of food in the mouth, healthy exploration of the mouth and mouth toys. This treatment may include manipulation of diet, recommendations for appropriate seating, and transitions to appropriate food. At this age the therapist's main goal is to educate and train the parent. The treatment session may focus on underlying conditions (e.g., proximal stability and sensory defensiveness). The parent will be the direct caregiver, with the therapist observing, making recommendations and educating the parent. Homework will also be given.

At the age of 3 years, the therapist will take a more active role interacting with the child and manipulating the environment to encourage positive experiences with food. Part of the session will address underlying conditions in a play like manner. First, the environment will be set up with equipment and materials which will encourage the child to participate in challenging activities that address sensory and strength related conditions. This will be followed by approximately 20-30 minutes of oral stimulation with food/non-food items. Skills will be demonstrated and reinforced with positive feedback. The therapist will gently establish a routine for this part of the session, and there will be expectations for the child's participation. Children tend to become willing participants when expectations are reasonably within the child's skill level.

Goals of feeding treatment include eliminating barriers to oral feeding. These may include strength/stability, sensory defensiveness, oral motor, as well as managing reflux and bowel related medical issues.

Therapeutic strategies to overcome common complaints…

The advantage of individual feeding therapy is that it can accommodate the specific needs of an individual child. The following are some common feeding issues that parents have raised and *my* typical recommendations for feeding treatment.

My child will not take the time to eat. He won't sit.

Set up a routine for feeding, even if your child is a non-eater. Make this oral playtime. Children between l8 months and 3-4 years old may be too busy to sit for something that is not their favorite thing to do. Make sure the child is comfortably positioned in an appropriate seat. Ideally, the child's knees, hips, and elbows should be flexed at a 90-degree angle, and the feet should be firmly placed on the floor or a footrest. (The chair may need to be modified or extra supports added.) A tray or child's size table is extremely helpful. Have novel toys available, special toys, which are only used at this time. The mealtime should last approximately 15-20 minutes maximum as tolerated by the child. Distraction may be helpful in lengthening the duration of the mealtime for the slow eater. Make this a pleasant experience.

My child eats or drinks small amounts over the course of the day but refuses to eat meals.

Children eat because they are hungry. If they eat or drink continually throughout the day, they may not be hungry enough to eat a meal, especially those with a poor appetite. Try to keep about 4 hours between each meal for the child 18 months and older. This will develop a cycle of fullness and hunger, which is important for a child. Try to minimize the amount of juice a child consumes as this may decrease their appetite.

My child is tube-fed all night and he won't eat anything in the day. He never seems hungry.

If a child is getting all his nutrition at night he won't be hungry. Talk to your nutritionist about moving towards a typical mealtime schedule e.g. breakfast, lunch, supper and snack. If you can spread the feeding over the day you will have more time to encourage a full-empty cycle which may encourage hunger.

My child gags at the sight of food.

Your child may benefit from desensitization treatment. He may be experiencing sensory defensiveness which produces a visceral response.

My child gags when food is placed in his mouth.

Your child may benefit from an oral stimulation program to desensitize his mouth. This program will involve play with various textured toys in enjoyable mouth play.

My child will eat creamy puree foods but will not tolerate any other textures.

What I typically recommend is to gradually increase the consistency or

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Continued...

(Group Therapy, continued from page 9)

negative learned behaviors that might have developed in the home environment.

Parents generally observe the group treatment sessions. This offers parents time to meet, network and share information with fellow parents. This is often seen as a break time. The parent is not responsible for the child's "performance" at mealtime. It is a time to watch, observe and share.

I have found that one of the greatest learning opportunities for me is to speak with parents as they are observing. Parents know their children the best. Their observations are key to facilitating the next steps in treatment. The information that is exchanged amongst parents assists in developing treatment plans and developing the group activities. Many parents have shared that it's nice to see that there are other children and parents who struggle with mealtime. When food is thrown in a group session, it is an opportunity to see that this happens even with the "professional".

Mealtime is a social event. As adults, we often plan our activities around food. We chat as we enjoy the different tastes. Family mealtime is a social, learning experience. It's a time to talk about the day or share time as a family. These are some of the principles underlying group therapy. ❑

Both group and individual therapy have been extremely beneficial for different reasons. For us it was timing. When we started with group our daughter was not having any real social/oral or feeding experiences. The social and peer aspect of the group helped her WANT to have the oral/feeding experiences that the other children were having. As our daughter's mouth became desensitized, her confidence increased. Now, that she has emerging feeding skills individual therapy focuses on her particular needs.

(Individual Therapy, continued from page 11)

thickness of the puree. This can be done in many ways by using additives with the purees (e.g. cereal, "Thick It", cornstarch, or breadcrumbs). This will make it necessary for the child to move the food around in the mouth, facilitating increased stimulation in the mouth. This needs to be done carefully under the guidance of your feeding specialist.

My child shows interest in solids but cannot chew.

Again try thickening the foods gradually. If the child manages this well then you can move to chewing. There are various devices that can be purchased in which solid foods can be placed in a mesh-like bag. This allows the child to practice chewing and tasting food without allowing the food to escape into the mouth. Children tend to like this as they can taste the food and crunch but have little risk of choking on the food.

My child appears to enjoy eating however only eats a small amount.

Volume is a very difficult issue to overcome. Some children may never be big eaters. The important issue here is to make sure that the food your child is eating is calorie packed. Your nutritionist will be helpful with this. Some strategies that may help are to combine liquid and solids at meals. Some children have an easier time drinking and could potentially drink an additional 4-6 ounces of milk or a high calorie drink.

My child pools the food in the front of her mouth and has difficulty swallowing.

Placing the food toward the side of the mouth and developing the tongue's ability to move may help this. Also, if this causes difficulty swallowing then sometimes a drink may help clear the mouth. Children who tend to do this do it to control the food. They may have difficulty with bolus size and therefore pool it in front until small amounts can be sent back for a swallow. These children need more experience with varied size boluses on their tongue.

How do I find the right tube-feeding schedule for my child as feeding therapy progresses?

It is indeed a challenge to create a feeding schedule that allows a child to experience the normal hunger-satiety (empty-full) cycle, while still receiving needed calories and fluid volume. The most ideal feeding schedule is 3-4 daytime boluses (the bolus size depends on the age and size of the child), typically breakfast, lunch, and supper. Oral feeding can then be offered prior to tube feedings and calories eaten may, under the care of a nutritionist, be subtracted from tube feeds. Nighttime feeds may continue to be necessary, however, when a child can only tolerate slow titration over a longer period of time, or when the full amount of calories/volume are tolerated in the daytime schedule. Fine tuning this is challenging as nighttime feeds often interfere with morning hunger. In many cases, it is a gradual transition from slow titration feeds to bolus feeds. Finding the right feeding schedule can be tricky and must be worth the disruption to the child. Special thought must be given to those children who become sensitive to changing their schedules or who have a tendency to vomit.

Any of these strategies should be used cautiously and only under the direction of a qualified professional. Each child's course of treatment and response to treatment is so individual and so are the strategies. The most important things are to hang in there, learn to read your child's body language (it often is extremely revealing) and develop achievable expectations and pleasant routines. Seek out help early.❑

One Child's Story...

Our preemie, 100% tube-fed 1.5 yr. old with severe reflux, came home from the NICU using the "mini-haberman" bottle. We had tried EVERY nipple, bottle, and fluid-containing contraption we could get our hands on. Although the mini-haberman bottle worked the best, it was still a 30 minute session for about 1-ounce of nutrition. Over the course of weeks, the volume she sucked declined as her reflux symptoms worsened. Dismayed, we stopped trying to bottle her on a regular basis. We brought her to the feeding team at our hospital every 3 months, and had OT/PT therapy through EI to work on oral motor problems and trunk strengthening. Despite all this support we felt extremely frustrated, as if we were missing some key pieces to help prepare her to learn to eat. Through parent and professional contacts, we were given the following advice. Please keep in mind that our needs were specific to her lack of oral motor skills, as well as her low trunk tone, sensory and reflux issues.

Our PT suggested using the R.I.S.S. (Dr. Rice Infant Sensorimotor Stimulation) 3 times daily on an empty stomach before bottling sessions. This is a massage program designed for preemies, used as a way to warm up the senses, as well as for other benefits. PT also worked on strengthening her trunk, and I requested exercises we could do at home without special PT equipment.

Our OT helped us with posturing issues. Throughout the day our daughter made various back arches, head dropping to shoulder and other reflux-type movements, which often escalated into vomiting (sometimes with such force as to block her airway). We had let her posture, thinking it was her way of dealing with the possible pain of the reflux. We learned we should instead correct these postures as they happened, because the pressure in her stomach was increased by these movements, which then facilitated vomiting. To correct it, we had to gently position her head in normal alignment with her spine. If sitting, we would support her trunk in an upright position, have a pummel between her legs, and use a foot rest. This really did help, although it was challenging as she became a toddler to correct the postures as she ran around. In addition, OT helped us set up an obstacle course in our SMALL apartment to challenge her balance (which increases trunk strength). This was later used as a warm up for eating when she outgrew massage. We would vary the obstacle course to make it more interesting as her development progressed. Pillows, blankets, soft chairs or couches were used to make this happen. We would do the obstacle course in the morning before her first "feeding".

Following the obstacle course, we used a highly structured program to get into her mouth and prepare her oral cavity. We began with the Wilbarger brushing protocol using a surgical scrub brush, then a wash cloth, NUK brushes (hand-held types and rubber finger brush), and finally vibration. We took pictures of her with each of these in use and put them into a book that we called the "GOOD EATING BOOK". Next, we inserted pictures of her with food or drink on a tray. This became a great help to us with our routine! She knew what to expect, and we would have her participate by turning the pages, and giving her a set of her own tools to try to "use". Which, by the way, she eventually did correctly! There were tears in the first few months, but we did hand clapping after each page was completed, and she is now her own biggest eating fan. We used the Raffi music song "Brush your teeth" to sing along. Although we ended the sessions in the chair with foods, this was the shortest part of the routine (10 minutes max). We kept this upbeat and offered one food type at a time, and gave her control of the food and a place to put foods once "all done". We used sign language "more" and "all done" to give her control since she was not yet verbal. We always told her what was being offered and encouraged touching first (later adding in smell, kiss, lick, bite, chew- IN THAT ORDER) as she progressed. At first, it was very slow and discouraging (food was not touched at all, or simply dropped into the all done spot) but over time she slowly progressed. When she wouldn't even dip her finger in the food we still praised her for sitting in the chair. We modeled what was expected with the foods ourselves. We always ended the session on a positive note, even if it has been horrible. Some claps and a kiss goodbye to the food or whatever was within her reach. When she ended terrible sessions we would say next time we will do "more" (sign) and she would nod her head and get a kiss from us. When she did something more challenging, we would praise her and take her out of the chair and do a goofy thing she liked such as the hokey pokey or something. (A picture of her doing the hokey pokey is the last page of her "book".)

Finally, we joined a feeding group which has given her a whole new idea of eating socially and watching other children eat. We also let her see us eating and drinking whenever possible, and let her explore our foods when she wanted. As she tasted foods, she would often gag or vomit because the experience of the food was so overwhelming on a sensory level. We remained neutral in our response, and commented on what was happening to the food. "Yes, the food is on your tongue". We would help her to see she could wipe it off if she needed to, and even if she vomited or blocked her airway, we remained calm to HER, and flat in our response "it is in your mouth, you are okay, we can take it out". We added a mirror to the routine so she could see herself once the food was on her lip, or on her tongue, etc. This would give her the visual image of what that sensation was.

Our Next Newsletter

Nutrition and the Tube-fed Child

The Fall 2001 issue of *Kids with Tubes News* will address various aspects of Nutrition. We would love to include your input on this topic. If you would like to contribute a story, recipe idea, or tip, please send your article to info@kidswithtubes.org or Jill Crisman at 22 Woodpark Circle, Lexington, MA 02421. The deadline for submissions is October 1, 2001. Do it now so that you don't forget!

Thank You

Kids with Tubes is supported by donations from institutions and families and friends of tube-fed children. Donations of all sizes are welcomed and appreciated.

This issue of *Kids with Tubes News* has been produced with funding from New England Home Therapies and MeadJohnson Nutritionals. Kids with Tubes is grateful to these companies for their generous support.

Recent Quarterly Seminar Summaries

Tube Tips

On January 13, Sharon Markowitz, Pediatric Nurse Coordinator at Dartmouth Hitchcock Medical Center, New Hampshire led a discussion covering tube tips. Approximately 20 people shared ideas and concerns surrounding typical tube-related issues. Several families whose children have recently had tubes placed attended. They got many good ideas for caring for the stoma, avoiding granulation tissue, and preventing plumbing mishaps!

Transitioning to Oral Feeding

On April 7th, Margaret Walsh, M.Ed., OTR/L addressed the group. Approximately 45 people attended. Margaret reviewed important background information about motor and sensory development, as well as sensory processing and how deficits in these areas can lead to feeding issues. She outlined different types of treatment, emphasizing sensory motor strategies to improve oral feeding skills. She also described how a behavioral approach could be combined with sensory motor strategies to improve oral feeding skills. Margaret showed a video demonstration of a child participating in the oral motor, sensory stimulation and motor coordination warm up, as outlined in the handouts provided. She also reviewed handouts on the developmental food continuum and discussed several strategies for helping children achieve oral feeding. Margaret's lecture was followed by stories from two parents who discussed their individual experiences with their child's transition to oral feeding. A lively dialogue followed.

New England Home Therapies generously provided the meeting space and refreshments for these Quarterly Seminars. Kids with Tubes appreciates their ongoing support.

Upcoming Quarterly Seminars

July 14, 2001
Picnic

October 13, 2001
Therapies for the Tube-fed Child

Dates and topics are subject to change. Refer to the Quarterly Seminar announcements for exact time and place. Pre-registration is necessary by calling (781) 275-0469.

Tube Tip

The following tip is provided by parent Jodi Zwain:

Just a little "hint" regarding the nighttime tube feedings. Buy several waterproof mattress pads. Buy several sets of fitted sheets. When you make the bed, layer a mattress pad, sheet, mattress pad, sheet, etc. This way if the pump/tube leaks at night, all you have to do is strip the top layer, and another clean one is waiting for you.

Do you have a tip to share with others in the Kids with Tubes community? We'd love to include it in our next newsletter. Or, if you are struggling with a problem that others may have solved, send it to us. Maybe others can provide a solution. Please send it to info@kidswithtubes.org.

To Learn More on These Topics...

Children between 0-3 years may be eligible for home-based Early Intervention (E.I.). No formal referral is required. Pediatricians, local hospitals, and Departments of Public Health will know which E.I. serves your geographic area. Older children may be eligible for school-based or outpatient services. Raise concerns with your pediatrician and/or teacher/school system.

Some resources for treatment:
HealthSouth Rehabilitation Clinics--can also do free screenings
Occupational Therapy Associates
Pediatric Feeding Team at major hospitals/ colleges and universities

Some resources for sensory integration, oral-motor, feeding, and mealtime equipment, books, tapes, web-links and more.
Equipment Shop
www.equipmentshop.com, 800-525-7681
New Visions
www.new-vis.com, 804-361-2285
Sensory Integration Network
www.sinetwork.org
Rice Infant Sensorimotor Stimulation (RISS)
www.cradlecare.com
Therapro
www.theraproducts.com, 800-257-5376

Some recommended books:
Childhood Speech, Language, and Listening Problems: What Every Parent Should Know,
by P.Hamaguchi
How's Your Engine Running?
by S. Williams & S. Shellenburger
How to Get Your Child to Eat….
by Ellyn Satter
Making Sense of S.I.
by Jane Koomar
The Out of Sync Child
by Carol Kranowitz
Pre-Feeding Skills,
by S.E. Morris & M.D. Klein
SenseAbilities: Understanding SI
by Maryann Golby Trott
Sensory Defensiveness in Children Aged 2-12: An Intervention Guide for Parents and Other Caretakers
by P. Wilbarger & J.L. Wilbarger

Regional Support Groups

Kids with Tubes facilitates informal regional support groups. The groups are organized by parent coordinators throughout New England. Many of the groups will be posting their meetings in this newsletter. These meetings provide opportunities for discussing individual experiences, tips, and concerns. Parents are invited to attend any meeting that is convenient for them. You should contact the coordinator of the meeting in advance so that she can notify you of any last minute changes. If you live in an area that is not currently served by these groups, and you would like to serve as a parent coordinator, contact Jill Crisman at (781) 402-0216.

Newton, Wellesley, Framingham Massachusetts Area:
Please call Marlene Shapiro at (508) 788-0632 for meeting time and place.

Stoneham/Somerville, Massachusetts Area:
- 1st Tuesday of every month at 7:00 PM at a group member's home

Please call Beth Corvi (781) 438-5249 to RSVP and get directions to the meeting location.

Western Massachusetts Area:
Please call Kathy Smiarowski (413) 247-9980 for meeting time and place.

Upper Valley (New Hampshire and Vermont) Area:
Please call Helen Norton at (802) 785-4615 for meeting time and place.

Connecticut:
- 3rd Thursday of every month at 7:00 PM.

Please call Karen O'Hanlon at (860) 693-1616 for location information.

Kids with Tubes

support for parents and caregivers of tube-fed children

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Kids with Tubes

Support for parents and caregivers of tube-fed children

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WE'RE ON THE WEB!
www.kidswithtubes.org