

# CHILDREN WITH FEEDING TUBES

## Part 2: TREATMENT PROGRAMS

### When should a child be referred for treatment?

Many infants and children are referred for treatment of their feeding issues in infancy. Others are not referred until they are older. There are many advantages to beginning a treatment program as soon as tube-feedings are recommended. Treatment programs can help educate parents about tube-feedings, can prevent problems from developing and can optimize oral-motor control and oral enjoyment for exploration and feeding.

There are many different approaches to treatment for children with severe feeding challenges. Some programs emphasize feeding the child and measure progress by the amount of food that the child eats at a meal; others focus on providing exercises for the mouth to improve coordination for sucking and swallowing. Some use a strong behavioral approach; others use a sensorimotor approach. Still others use an eclectic combination of these approaches.

### What is a comprehensive oral-motor treatment program?

The primary goal of a comprehensive oral-motor treatment program is to develop a positive and enjoyable use of the mouth in all areas. The treatment focus is to develop the appropriate use of the mouth for oral exploration, sound play, and as much oral feeding as possible. Food and liquid are not essential to the program, however, (especially in the initial stages) and may not be included at all if the child has a severe swallowing disorder. Treatment strategies provide opportunities for the development of sensory awareness, perception, and discrimination within the mouth, and the use of oral movement to explore and understand the world of toys, clothing, body parts, sounds, food and liquid. Food and liquid may be introduced to provide smells, tastes, temperatures, and to elicit specific oral movements when the child is medically able to handle them. Treatment always looks at the effects of the mouth on the feeding relationship and looks at the physiologic systems that impact on the mouth. It looks at the mouth as a part of a whole child who is a part of a whole family! Oral feeding is the by-product of a total program, not the major goal. As a result, there

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is an ongoing sense of gain and accomplishment throughout the program that is not diminished by the slow attainment of oral feeding abilities.

Comprehensive oral motor treatment provides support for the child and family, wherever they are on the journey between tube-feeding and oral feeding. Guiding children from tube feeding to oral feeding is a process that involves many steps and many considerations. It is not usually an either/or proposition with either tube-feeding or oral feeding. Most children develop skills from their own starting point on the continuum. They let us know if and how fast they can move along. Their medical status, growth and development of oral skills determine the path taken along this continuum. Some children remain tube-fed for extended periods, but need to continue to build the oral skills for oral exploration, swallowing, and oral hygiene. Some children become oral feeders for solids and continue to take liquids by tube. Oral skills for chewing and swallowing need to be developed or maintained. Other children move to become complete oral feeders by day with some extra nutrient supplementation at night. Still others move off the tube and onto complete oral feedings. When therapists focus only on feeding as the major goal and component in the program, they narrow the scope of the program and eliminate many programming aspects that are essential to help the child progress. The result may be frustration for the child, the parent and the therapist. Comprehensive oral motor treatment supports the child anywhere on this continuum. The ultimate success of a (comprehensive) oral motor treatment program is not measured by the child's progression to total oral feedings. It is measured by the emergence or enhancement of a child's ability to enjoy the mouth and use it for exploration with sensory awareness and discrimination. It is measured by the growth of a communicative child who uses vocalization, sound play, and gesture to interact with others.

### **What parts of a child's experience influence the treatment program?**

Children who are tube-fed demonstrate a multitude of different feeding issues and sensitivities depending on each child's oral experiences with and without foods, medical status, previous and current interactions

around mealtimes, overall physical skills and specific oral skills. Let's look at the multiple influences on the child and family that affect the goals of the comprehensive oral-motor treatment program.

#### **Oral Experiences**

Children's prior and current oral experiences strongly influence how they approach oral stimulation and feeding. Abnormal or aversive responses to oral stimulation occur frequently when the infant has been deprived of positive sensory input to the mouth. Because many of these children require invasive procedures such as prolonged ventilation, suctioning and tube-insertion, they may develop a belief that the mouth is an unpleasant place. They avoid using the mouth to explore and learn because it is uncomfortable. They become wary and watchful of anyone who would approach the mouth. Their attempts to protect or guard the area become deeply ingrained.

Some infants have tubes placed immediately if their medical status or poor sucking skills warrants it. These children may then have had no experiences with normal sucking and swallowing. These children may "forget" how to use existing sucking and swallowing skills, or may not have ever developed them. They may not have any experiences with tastes and textures and may end up missing the critical periods where the learning of these skills is physiologically most easily achieved.

#### **Medical Status**

Many medical conditions make mealtime enjoyment difficult and healthy growth impossible. Children with cardiac difficulties may fatigue so quickly that mealtimes become exhausting experiences. Respiratory difficulties are observed with high frequency. Respiratory issues contribute heavily to exhaustion and poor incoordination of sucking and swallowing patterns with breathing. When given the choice of breathing or eating, these children choose breathing. Respiratory control problems contribute to fearfulness and caution as a general approach to new or unsuccessful experiences. They may become exaggerated when the child produces excessive mucus that collects in the pharyngeal airway. Children who aspirate may eat less because of their internal realization that the food or liquid is not good for them. Many children have other disease processes,

medications, or severe allergies that negatively influence appetite. Gastroesophageal reflux can strongly influence mealtime experiences. Reflux is unpleasant for the child and caregivers. Constant acid irritation of the esophagus can reduce the infant's desire to take food by mouth because of the discomfort. Appetite is suppressed. Children quickly learn that eating means discomfort or pain. They often avoid or reduce eating by mouth to avoid this discomfort.

Children with many medical conditions have learned that mealtime is no fun! When supplemental feeding tubes are placed, many realize they feel so much better with a full tummy, or they have to work so much less at feeding that they voluntarily stop eating by mouth. Their medical conditions need to be treated and then they may have to re-learn that eating can be enjoyed.

### **Mealtime Interactions**

Children's personal-social interactions surrounding meals strongly influence both their attitudes about the meals and their development of appropriate oral skills. Parents of tube-fed children often are guided in the mechanics of tube feeding, but not in the emotional aspects of feeding. If tube-feedings become a mechanical process, children and parents can miss out on the nurturing, trust building and attachment and bonding aspects of the mealtime relationship. Emotional responses to eating can express themselves as colic, irritability, gagging, retching and vomiting and an unwillingness to try new things in the mouth.

Sometimes by the time the tube is placed, parents and therapists have tried everything. They have added calories, encouraged, prodded and begged. They have bribed, coerced, and tricked. Sometimes the child has been forced to take in calories by well meaning parents and relatives who are just trying to help the child grow. The overall effect may be a child who cringes when he sees the food coming. Mealtime may have become a time of stress for all. The positive aspects of the mealtime relationship have been lost. Neither child nor parent enjoys the meal any longer. The positive mealtime relationship must be reestablished.

### **Physical Skills**

Changes in muscle tone influence the effectiveness and coordination of skills for eating. Many tube-fed children have neurological issues that affect muscle tone causing hypertonicity, hypotonicity or fluctuations in tone. These tone changes affect the child's posture for eating and respiration. Poor trunk posture will influence head and neck control. It also impacts on the internal organization of the digestive process. Children who round their back in sitting often "bend" right at the level of the lower esophageal sphincter. This can promote or aggravate gastroesophageal reflux. Hyperextension of the neck, accompanied by scapular adduction and shoulder girdle elevation, is seen as the primary movement characteristic of many of these infants and young children. This position strongly influences oral and pharyngeal control and affects the skills of bolus preparation and the safety of swallowing.

### **Oral Skills**

Some children have poor oral skills that lead to the tube placement. Others develop them. Infants may have poor oral skills for many different reasons. Disorganized and arrhythmic sucking patterns are characteristic of many neurologically impaired tube-fed infants. Often a clear sucking rhythm is lacking. Movement may be further disorganized when touch or pressure is applied to the tongue with a nipple or spoon. Some children's oral skills at birth do not support good growth. When a feeding tube is given the child may stop eating orally so that they do not have to work so hard. These are children who often seem to forget sucking and swallowing skills. When organizing input and experiences are not provided early, critical periods of development may be missed. Thus when intervention is finally provided, the child may have bypassed the physiological stages at which learning is most easily achieved

Swallowing disorders preclude the development of successful oral feeding. Many children have difficulty using the tongue and lips to organize the bolus of food or liquid in the oral cavity and project it backward for the swallow. Small amounts of food may drip over the back of the tongue without eliciting a swallowing reflex. When the swallowing reflex fails to occur, the airway is open and unprotected and the upper end of the esophagus does not open to allow food to pass.

Aspiration of food into the lungs is the natural consequence. Some children have a delayed swallowing reflex. Instead of the pattern triggering from the backward movement of the tongue and the stimulation of the anterior pillars of fauces, swallowing is elicited after food or liquid has collected in the valleculae or pyriform sinuses. Although the swallow occurs, a portion of the bolus may be aspirated before or after the swallow. Some tube-fed children develop overreactive or underreactive responses to oral stimulation. These may occur with touch to the face and mouth, to textures, tastes, smells, or temperatures. These will need to become more normalized as a part of an oral treatment program.

### **What are the components of a comprehensive oral-motor treatment program?**

We could describe a comprehensive oral-motor treatment program for these children as being a holistic program, based on a global view of the needs of the child and the family. Many aspects of interaction, sensation, movement, learning, social skills, and communication are included. The focus of treatment is not strictly on the function of the mouth in feeding. The following components of the program must be considered in the development of a successful treatment program for children who are tube-fed.

#### **Establishing a Positive Mealtime and Treatment Relationship**

A comprehensive oral treatment program must begin with the re-establishment of a positive mealtime relationship for the parents and child at home and for the therapist and child in treatment. The child's mealtime relationship with both the parents and therapist is extremely important to the success of the program. Adults come to the relationship with experiences (both positive and negative) with feeding and oral treatment. The abilities of the therapist to convey the principles of the oral program and the abilities of the parent to understand and carry out recommendations at home also will strongly influence the program. Children come to the relationship with their own temperaments, experiences, attitudes about mealtimes, and skills. All of these influence where, when and how to begin an oral treatment program

with the goal that the child will enjoy oral exploration and have positive feelings about the mealtime.

Therapists can use many of the same strategies in establishing positive relationships with both the child and parents. Parents need to be reminded about the importance of positive touch surrounding tube-feedings, as well as throughout the day. Positions for tube-feedings, when possible, should involve the same supportive, loving holding that a baby would receive during breast-feedings and bottle-feedings. In the same way that a parent would pause a feeding for burps or discomfort in bottle-feeding, the parent of a tube-fed child can learn to be sensitive to signs of discomfort or fullness and create comfort pauses. Parents can be shown how to "listen" to the body language of widening eyes, changes in facial expression, signs of discomfort, and wiggling or arching. These may be cues to pause, slow down, or discontinue a tube-fed meal.

For children who have had negative experiences around the mouth, parents need to understand the importance of positive loving touch, not only orally, but also over the whole body. Positive and loving touch can be an important component in the re-establishment of trust in the feeding relationship. Touch and movement can be used in a highly communicative, interactive fashion during treatment and daily care. Pediatric massage can incorporate loving touch into the daily routine of the child. Parents can play interactive touch and oral stimulation games around the face and mouth. Kissing can become very powerful and rewarding therapy for both the parent and the child. Favorite stuffed animals or dolls can help with the kissing and facial touches in a safe and familiar fashion. Combining songs with touch activities can provide a distracting, playful and predictable rhythm.

Children must be given some control over the mouth in order to trust those around them. They must be allowed to let the parent and therapist know what feels good and what does not. They need to trust that they will no longer be forced to have unpleasant, frightening experiences around the mouth and mealtimes. They must be allowed to "give permission" by actively participating in the presented activities or meals. Each child can learn to give permission by leaning forward

into the experience, or by opening the mouth. Children will develop trust if the focus of treatment is to make the oral experiences enjoyable with their active participation. Programs that try to desensitize the child by pushing unwanted “stimulation” into the mouth are incompatible with the goal of oral motor and mealtime fun.

In comprehensive oral-motor treatment, the therapist and parents follow children’s lead. Children know what they can handle, what feels good and what does not. The adult and the child establish a trusting mealtime relationship where the child “gives permission” for the activities presented. The therapist and child explore the aspects of oral treatment together. It is not a program where the therapist “does to the child”. They “dance together”.

### **Establishing a Relationship Between the Mouth and Feeding**

Children who are fed by tube from early infancy can forget that the mouth has anything at all do with the feelings or the satiation that comes with a feeding. Oral feeders are hungry, see the breast or bottle, eat and then feel full. They easily learn to relate the feelings of fullness with the mouth and eating. Tube-fed babies receive a feeling of fullness through the tube passing into the nose or stomach. In the child’s experience, the mouth may have no relationship to the feeding. Some children who are on continuous drip feedings are fed all day. They never have an opportunity to experience hunger or satiation. This further complicates the relationship between the mouth and hunger. Early treatment can allow for associations to be made with smells and tastes during tube feeding by pairing oral-feeding stimuli with the tube feeding. Stimulating a nonnutritive suck with a pacifier or finger during tube-feedings can result in reduced irritability, increased weight gain, and easier transition to oral feedings. Babies can also suck on the bottle or breast while a tube feeding takes place if there are no swallowing difficulties. This can actively relate the feeling of fullness to the mouth and the smells and touches surrounding feedings. Whenever possible, a feeding schedule is established that allows for space between meals to allow for hunger to develop so there is a hunger fullness cycle established.

### **Reducing the Impact of Medical Conditions That Influence Feeding**

Ongoing medical management of the conditions and disease processes influencing feeding and appetite must be a priority. Though physicians usually control this treatment, the feeding therapist can play an active role in communication with the medical team. It is important to work in partnership with physicians to provide feedback about how different procedures and treatment options are influencing feeding, appetite and overall goals in oral-motor treatment. Although the feeding therapist does not do medical procedures or prescribe medications, there are some things they can do to support the medical management of these children.

The presence of gastroesophageal reflux, for example, is a pervasive factor in developing goals for an oral-motor treatment program. The physician will treat the reflux medically, but the feeding therapist and other team members may need to help the family deal with management of the daily reflux experiences.

Work in therapy can explore the child’s tolerance of feedings, feeding sizes and positioning during and after meals. Some children improve just by being fed smaller meals more often. Less volume can reduce the stress on the lower esophageal sphincter and stomach emptying. Thickening feedings with one tablespoon of baby cereal per two ounces of formula may reduce vomiting episodes. Some children have fewer reflux episodes when positioned prone, or on their right side. This can be accomplished with prone positioning on the parent’s lap or prone in bed. Elevating the crib mattress to a thirty-degree angle or providing a pillow wedge with a thirty-degree angle also helps reduce the number of reflux episodes. Some older children are helped by being fed in an upright prone position using a prone-stander propped at a forty-five degree angle. Non-nutritive sucking on a pacifier during the infant’s tube feedings also may reduce gastroesophageal reflux and enhance digestion.

Reflux has many trigger points that can complicate the feeding process. The therapist and the parent can explore these together. Some children with reflux have frequent vomiting episodes. Others gag frequently and have trouble differentiating between

the need to burp and the need to vomit. Still others become overly sensitive to sensory changes in the mouth and pharynx and have difficulty transitioning from thin liquids to purees or purees to textured solid foods. Some children induce gagging as they explore the mouth with fingers or toys. Children who have had an extensive history of reflux often end up having gagging and vomiting available to them in their repertoire of “things to do to get attention”. This can lead to voluntary use of gagging in daily interactions. A hospitalized infant, for example, may discover that vomiting is a sure way to engage the one-to-one attention of the nursing staff or other adults. It can become a way in which a helpless child can show power over coercive adults. The communicative aspects of reflux and triggers for gagging need to be explored carefully in the development of the comprehensive oral-motor treatment programs.

### **Optimizing the Comfort and Enjoyment of Tube-Feedings**

It is difficult to begin or maintain a positive oral treatment program if the tube-feedings themselves are aversive. Parents need to be educated in the optimum ways to provide the tube feeding and in reading the child’s cues of feeding related discomfort. The rate of formula delivery through the tube can be changed easily by raising or lowering the syringe. Some children have a very small stomach capacity that needs to be expanded gradually. This often requires increasing the formula volume slowly. Because, however, the stomach volume is being increased, it is always being pushed to maximum capacity. This can cause gagging, retching or vomiting if it is done too rapidly and without regard for the child’s cues of discomfort.

Some children have increased sensitivity for bolus feedings after a Nissen fundoplication procedure. There can be excessive bloating, gagging or retching. In extreme situations the surgery can become undone with the intensity of the retching. This is very uncomfortable for the child and causes a reversion back to the pre-fundoplication symptoms of gastroesophageal reflux. This situation negatively impacts feedings. Therapists can help parents explore their children’s tube feedings and find the combination of bolus size and method of delivery that causes the least stress. This may involve giving the feeding over

a longer time period by slowing the rate. Over time the feeding time can be gradually decreased. For some children slowing the rate is not enough; there may need to be actual pauses or breaks within the feeding. Other children need to be given smaller feedings more often to reduce the stress on the stomach. Still other children may need to return to continuous drip feedings to reduce the stomach stress and gradually work up to larger boluses.

Changes in bolus size and feeding rate need to be done very slowly. Children often remain on a smaller bolus size or slower feeding rate than their bodies can handle because changes are too sudden. Increasing bolus size by 5-10cc (1/6-1/3 ounce) at a time may take longer, but may allow for a gradual adjustment by the gastrointestinal system that is accepted without distress. It is also important to remain at the new rate for at least a week to allow the system to adjust and accept this as a comfortable level. Again, if increases are made too rapidly, some children’s gastrointestinal systems will rebel and the child will increase symptoms of distress and discomfort.

Bolus size can often be increased more easily initially by using boluses of water. The stomach stretching provided by water boluses may be better accepted initially than calorically dense formula boluses because water moves through the stomach more rapidly. This gives the child an initial stimulus that stretches the stomach but does not continue to the point of discomfort. Digestion is not involved with clear water. This enables many children whose discomfort is associated with prolonged periods of stomach fullness to learn that they can feel “full” for short periods without feeling ill. This is an important concept for children who have learned to respond to the initial stretch of the stomach with tension and anticipation of gastric distress. Working together with the medical team and the family, the feeding therapist can help promote the optimum positive associations with the tube-feedings. Regular water boluses should not be given to infants or to children with cardiac or kidney problems without discussing this with the child’s physician.

In optimizing the comfort, enjoyment and positive associations of tube-feedings, therapists and team

members can explore questions about dietary diversity and the possibility that the child's gastrointestinal distress may be related to an allergy or allergic sensitivity to the single formula. Some children are more comfortable and stop vomiting when a rotational formula plan is used. The child's dietitian and physician would select three or four very different formulas with different nutritional components. These formulas would be rotated so that a different one is given each day in the 4-day cycle. Small servings of a blenderized food can be mixed with the formula and given by tube once a day to alter the diet slightly and give different "taste and smell" experiences. Some children do much better with a formula custom-created of blenderized foods by the dietitian than they do with commercial tube feeding formulas.

### **Improving Postural Control of the Head, Neck, and Trunk**

Any oral motor treatment program should begin with a look at the child's whole body. To start with the mouth alone can ignore the basis for some of the oral difficulties. Work that builds or normalizes postural tone in the trunk and develops postural stability allows the child to release any holding tension in the neck, shoulders, arms, and legs. As tone is built up and stabilized with handling and sensory input, new automatic movements are facilitated. These include patterns that involve capital flexion (chin tuck with a straight neck) and activation of the lateral and diagonal control of the abdominal muscles. Greater neck flexion and a balance of flexion and extension for upright head control brings the tongue and lips into a more forward position and reduces inefficient posturing of the mouth and pharynx. As control is developed in the neck flexors and in the oblique abdominal muscles, greater stability is provided for the rib cage. This in turn allows for increased chest expansion during breathing. Activation of the entire abdominal-pelvic muscle girdle allows for better support of the stomach and abdominal contents and a reduction of colic, excessive burping, and gastroesophageal reflux. Contraction of the abdominals is also necessary for regulating vocalization for sound play and speech. Initial work is often carried out in supine, sidelying, and prone to enable the infant to develop a clear sensory feedback of the movement without having to deal with the added control required in antigravity positions of sitting and standing.

### **Improving Control of the Pharyngeal Airway**

At birth, infants are able to make the postural adjustments of the pharyngeal wall, which maintain the airway tube at a constant diameter regardless of head and neck position. If this did not occur, there would be constant changes in diameter as the tube bent with neck flexion and extension, and the tongue would tend to move into the airway when the infant was in supine. This pharyngeal airway maintenance assures the body of a constant amount of air inflow through a stable intake tube.

It is important to determine the extent to which the infant or child depends on compensations such as neck hyperextension or tongue protrusion to enhance the diameter of the airway. These compensations must not be taken away from the child through therapeutic handling without dealing with the underlying difficulties.

The increased production and poor handling of mucous constitutes a major difficulty in airway clearance for many infants and children. The reason for the mucous should be carefully investigated. Mucus is produced by the body as a secretion to lubricate tissue or as an excretion to rid the body of something that is inimical to the system. Thus, when one has a cold, additional mucous is produced as a binder to flush toxins out of the system. Increased mucous occurs when the body is not producing adequate elimination through the bowels or skin, when food has been aspirated, and when there is an allergy or sensitivity to foods, chemicals, or inhalants.

### **Using the Mouth to Explore the Environment**

Often tube-fed infants have missed the richness of sensory information that occurs in typical babies as they mouth everything that can get to their mouths. Babies mouth their own fingers, toes, bibs and rattles. They experience the sensory variation in mouthing provided by the breast or bottle, their own skin, fabric textures, and hard and soft plastic toys. The mouth feels surfaces that are smooth and rough, and sizes that are big and small. The jaw, lips, cheeks and tongue all respond to the shape and texture of the mouthed object. Holding these objects in the mouth provides one of baby's first opportunities to move the tongue separately from the jaw. The tongue learns to move to

the side, forward, up and down as it explores the sensory wonderland of mouthing toys. A discriminative type of exploration gradually replaces the earlier random generalized mouthing pattern. Oral skills expand and interpretation of information becomes more sensitive. Infants begin to find similarities in mouthed objects and experience contrasts of sensations. Clothing offers many sensory contrasts for the mouth. Young children can be encouraged to find zippers, buttons, and shoelaces with the tongue, and contrast the sensations with those produced by the surrounding fabric. The development of greater discriminative skills and stereognosis in the mouth improves sensorimotor organization and articulatory skills in children who do not have neurological impairment.

Helping children mouth their own fingers or toys can be a part of everyday life as well as a central part of an oral treatment program. The child's own body is the first toy. It can be used very effectively for mouthing. Fingers and toes provide a wealth of sensory information for the mouth. The feeling of one finger versus the entire hand can be experienced. Fingers versus thumbs can be explored with the tongue. The fingers can be laced together and both thumbs inserted into the mouth to explore a new sensation. There are many varied and wonderful mouthing toys available that can be explored with the child. When children are active participants in bringing toys to the mouth, they will integrate more sensory information from the toy. Children who gag easily typically handle fingers or toys that they direct to their own mouth more easily than toys put in their mouth by another person. Oral exploration can be paired with games and songs for further variation in activities.

When it is medically appropriate, children can take tastes off toys. Once a child has played with the mouthing toy and seems to enjoy it, it can be dipped in regular or diluted juice or broth to slowly introduce flavors. Taste and texture variations can thus be introduced slowly, always following the child's lead. Food tastes can be placed on the child's fingers or toes. As the fingers and toes find the mouth in play, the child instead of the therapist introduces tastes. Finger painting with pureed fruit or vegetables can be encouraged on the high chair tray or on a mirror. Gradually the tastes can be painted on the lips. With

the introduction of foods, the child is exposed to smells, temperatures, and visual impressions with the finger painting. Crumb textures can be introduced with the finger painting or on the mouthed objects. This new texture may not be so scary in a play activity or as a byproduct of mouthing a familiar toy. Feeding therapists must be very aware of their internal agendas as well as the child's response to the introduction of taste. A strong sense of trust must be built prior to bringing food-related stimuli into the child's play. When adults introduce tastes with the ulterior motive of tricking the child into eating, the strategy will often fail. When it is done as part of a program to expand the child's overall enjoyment of sensations, the child may initially reject the input. However, the child will frequently accept the taste on another occasion.

### **Normalizing the Response to Stimulation**

Many tube-fed children develop overly sensitive or undersensitive reactions to sensory experiences involving the mouth. It is important to help normalize the child's responses to stimulation. Whether the child's responses to stimulation are from negative oral experiences, from fear of new experiences or whether they are sensory or emotional based, treatment must progress slowly. Attention must be placed on building the child's trust in oral play and increasing the child's ability to get hands to the mouth and use the lips and tongue to explore the environment. The positive interaction between adult and child needs to be built gradually, allowing the child to gain confidence that the therapist is a partner in exploring the body and mouth – not another invader.

It is important to begin with sensory experiences that the child DOES enjoy. Find them. They do exist. They may be deep pressure-touch, soft touch, warm touch or vibration. Children may be drawn to their own fingers, a favorite toy, the bathtub or their mother's hand. When touch is introduced, it should always be presented so that children can see it coming. This avoids sensory surprises. Let the child reach out and be a part of the touch and play. Begin the exploration at the part of the body where the child is most comfortable. In many cases this is NOT the mouth or even the head. Initial touch may involve the child's foot or tummy. The games can then move the touch towards the chest, head, cheeks and mouth, as the



child allows. It is vitally important to listen carefully. If the last touch came too close and began to cause discomfort, the observant feeding therapist can shift the touch to a safer and more comfortable area.

Rhythm and music make these activities more fun and predictable for the child. If the touching is paired with a song, the child can anticipate a touch playfully. A song rhythm can be tapped along the child's body from the foot to the knee to the tummy to the chest and up towards the face. When presented in this fashion, children often are more comfortable by the time the touch nears the face than if the face were approached directly. Touch paired with movement can also help the child anticipate what comes next. When the child sits on a swing or therapy ball, movement can provide a rhythmical base for touching as the child moves closer to and farther from the therapist.

Variety, intensity and duration of stimulation are increased until the child's threshold for comfort and easy acceptance is reached. The therapist observes for any limiting patterns of tone or movement that have occurred in the past. The stimulation is increased gradually as the therapist helps the child to control or stop the undesired response. Focus is placed on finding ways to make the sensory input interesting, communicative, comforting, and acceptable while gradually pushing back the limiting threshold and building a more appropriate response and reaction.

### **Identifying and Facilitating a Swallowing Reflex**

It is critical to determine whether a swallowing reflex is present before food and liquid are used in the program. The feeding therapist can check for a swallowing reflex by observing the child's control of saliva and spontaneous swallowing or by using a straw or small medicine dropper to place tiny drops of water on the back of the tongue. A history that suggests chronic aspiration may preclude presentation of liquid. In either case, feel for the elevation of the larynx-hyoid complex in the neck and elevation of the root or base of the tongue. Observe whether the child chokes or coughs after small amounts of food or liquid are given. If there is no sign of a swallowing reflex, proceed cautiously working to enhance sensory and motor skills in the front of the mouth without using food or liquid. Initial work to achieve an appropriate swallow pattern can

begin by using toys, pacifiers or fingers that help the child increase oral-motor control. An effective swallow can often be triggered by work to increase the strength, duration, and timing of the suckle pattern. As respiratory problems become less threatening, swallowing function is likely to return.

Once a consistent swallowing reflex is achieved, it is difficult to be certain clinically that swallowing of liquids or foods other than saliva will be safe. Though the timing and components of the swallowing response can be analyzed through videofluoroscopy, the child must be able to swallow at least a third of a teaspoon of liquid mixed with saliva, for several swallows to get any reasonable information from the study. At this stage, the therapist may need to work in collaboration with the medical management team to introduce tiny amounts of liquid or puree for increased swallow and taste practice prior to a videofluoroscopy just to insure more useable information from the study. The appropriateness of this decision depends on many factors including the intactness of the swallow reflex, the child's medical history and current medical status and the therapist's experience.

Tube-fed children pose a challenge to the parent and therapist that is potentially frightening. In the back of each mind is the fear that the child might choke, aspirate, or die in the process of learning to swallow. Caution is appropriate; fear is not. It is much easier to prevent these problems than it is to deal with them. Postural drainage, suctioning, facilitation of a cough, and careful selection of the type and amount of liquid or food will sharply reduce the amount of conflicting mucus in the mouth and pharynx during attempts to swallow. The possibility of aspiration will be reduced by paying careful attention to positioning so the head is not in hyperextension, by developing the prerequisite oral movements before adding food for oral stimulation, and by thoroughly preparing the child physically and sensorially for swallowing.

Many infants and children will experience mild aspiration on the path to oral feedings. Since this is probable, foods must be selected carefully to reduce the danger of aspiration pneumonia and lung damage. A small amount of diluted water-based liquid is the least harmful. Food and liquid containing fat are less

easily assimilated by the lungs and should be avoided until there is no indication of aspiration. This includes dairy products, meat broths, and other animal foods. Foods that tend to produce an increase in mucus for the specific child also should be avoided. These may include milk-based products, grains, and some sweets. Fresh pureed vegetables and fruits are appropriate when semi-solids are added to the diet. Vegetables (if the child will accept them) are preferable to fruits because they do not rely on sweet taste for acceptance.

If there is a history of extensive aspiration, it is wise to introduce oral feedings where suctioning equipment is available. However, with good preparation and introduction of food only when the infant can handle it, this precaution is not critical. Work on feeding should be done only when the child is conscious and awake. Gentle oral stimulation may be done when the child is asleep or comatose, but food and liquid should not be placed in the mouth unless the child is alert and aware of what is happening.

#### **Facilitating a Rhythmical Suckle-Swallow**

Rhythmicity is the underlying component of all coordinated behaviors. When it is absent or distorted in sucking and swallowing, the resulting incoordination precludes successful oral feeding. The extension-retraction pattern of the suckle-swallow assists in moving a liquid or food bolus to the back of the mouth for the swallow. Because the suckle facilitates the swallow, swallowing often improves through concentrating on developing a strong, rhythmical, sustained suckle. This pattern occurs at a rate of about one suckle-swallow per second. This is the underlying rhythm-tempo seen in other systems, such as the walking gait and heartbeat.

Initially, the tongue is stroked in a downward and forward direction by the therapist's finger or by the infant's finger under the therapist's guidance. If there is any type of rhythm present in the suckle, it should be followed and gradually altered to fit the one-per-second rate. The use of music with a 4/4 rhythm and a tempo of sixty beats per minute (for example, largo and adagio movements of baroque music) can be extremely helpful in augmenting this underlying body tempo. Rocking at the same rhythm and tempo also can enhance the pattern.

As the suckling rhythm emerges, water, juice, or small amounts of pureed fruits and vegetables can be placed on the stroking finger. Eventually the stroking can be done with a plastic medicine dropper, a syringe, a modified pacifier, or a moistened cotton swab. This enables larger amounts of liquid or food to be added gradually to the rhythmical tongue movements of the suckle. When the child is able to take small amounts from a spoon, the rhythm can be sustained by using a downward tip to the spoon with rhythmical contact on the tip of the tongue. It is extremely important that this progression proceed slowly and within the child's physical and emotional tolerance. If too much liquid is presented, the child may automatically stop the rhythmical suck to defend a vulnerable swallowing or respiratory system.

#### **Improving Tone and Movement in the Jaw**

Because of the anatomical attachment of the other structures of the face and mouth with the jaw, problems such as jaw thrust, jaw retraction or exaggerated downward excursions reduce the efficiency of other parts of the oral mechanism. Opening and closing movements of the jaw are strongly influenced by the position of the head and neck. Treatment approaches that create a more normal balance between extensor and flexor patterns throughout the body will favorably influence the control of the jaw. Activities to normalize the child's response to oral sensory stimulation can reduce a tonic bite reflex when combined with handling and positioning to normalize postural tone.

#### **Improving Tone and Movement in the Lips and Cheeks**

It is important to work for active use of the lips and cheeks in drawing food and liquid into the mouth and retaining it within the cavity in preparation for swallowing. If the suckling pattern can be elicited from stimulation at the lips, the infant will have a better ability to control the intake. Playful games of patty-cake on the cheeks, vocalizing, patting the lips to make interesting sounds, and firmly applying face lotion to the cheeks can all help build tone in the face. Stroking firmly with a circular motion around the lips can encourage greater lip activity and a forward posturing for the suck. These activities should be offered in a communicative, interactive fashion, playing around the mouth while smacking the lips, making funny

sounds, or blowing raspberries. The stimulation from an electric toothbrush can stimulate tone and movement in the lips and cheeks. The stretch of the cheek as the toothbrush is cleaning the cheek-side of the teeth can promote a drawing in of the cheek and lip corners. Sometimes finger toothbrushes or a variety of infant tooth-cleaning options can be used.

### **Improving Tone and Movement in the Tongue**

The tongue is often hypotonic, thick, and bunched. Increased force and tone may occur during protrusion. The configuration often deviates from the normal flattened tongue with central grooving. This normal configuration provides a channel for passage of the bolus from the front to the back of the mouth for the swallow. Treatment approaches to improve tongue tone and develop a more appropriate configuration often include downward bouncing or patting on the tongue with the finger, a toy, a teething biscuit, or the NUK™ toothbrush trainer set. This is done in a context of sound play or with the rhythm of folk music. As tone increases, greater flattening and movement occurs. The tongue can be stroked to obtain a central grooving or lateral or upward movement. A rhythmical suckle-swallow then can be facilitated from the lips or tip of the tongue. Toothbrushing also stimulates tone and movement in the tongue. Brushing the center of the tongue can facilitate flattening and a more central groove while brushing of the sides can stimulate tongue lateralization. As the child becomes more comfortable with a range of sensations in the mouth, the adult can vary the input by using sponge brushes, finger toothbrushes, and electric toothbrushes.

### **Facilitating Voicing and Sound Play**

Vocalization and sound play are actively encouraged in all phases of the program. When the emphasis during oral-motor activities is shifted to play and vocalization, there is less association with unsuccessful or unpleasant past experiences with feeding. Emphasis is placed on combining respiration with vocalization and interesting sounds produced by the therapist, paired with easy movement of the child. Jiggling the chin, tapping the lips or tongue, and other physical maneuvers will encourage the child to produce sound. Older children may enjoy blowing bubbles while making noises.

With infants and children developmentally under the age of five months, and children unable to produce voice because of a tracheostomy or severe neuromotor damage, the therapist may produce sounds to get attention without requiring vocal interaction. With older infants and children who are able to vocalize may be able to make sounds in response or even imitate the adult. It is important to work for the sensorimotor experiences that provide speech production possibilities. The child's vegetative noises, vowels, and consonants should be imitated, reinforcing the production and creating a dialogue.

Various combinations of tongue, lip, and jaw movement can be practiced with sound and without food. Improved sensory discrimination and sensorimotor control for sound play can improve the similar coordinations involved in oral feeding. Vocalization provides greater action of the pharynx, larynx, and mouth, and may indirectly facilitate some swallowing and reduce mucus lodged in the mouth and pharynx. It also helps a therapist define the status of the larynx and any vocal fold closure difficulties. When the child has difficulty with vocal fold closure and airway protection during swallowing, work to improve vocal fold control during vocalization can be invaluable.

### **Programming Total Communication**

The tube-fed child who has neurological problems is at high risk for not developing oral speech communication. There are parallels between the movements and coordinations that develop in feeding and those that emerge in early sound production. Whether there is a causal relationship between feeding and the normal acquisition of speech motor control is debatable. It is clear, however, that infants and children who have severe disorders of oral control for feeding will have similar difficulties with the finer coordinations needed for intelligible speech production. Deprivation of oral-sensory experiences that organize movement for speech can have a profound effect on speech and language development of the tube-fed child, even when there is no neurological impairment.

Programming for infants above the developmental age of eight months should include a strong emphasis on total communication. By that age, infants have a sense of causality and are capable of communicative

intent. The development of turn-taking behaviors, expansion of means-ends abilities, and eye-gaze rules should be included in the program. Emphasis should be placed on using simple gestures (waving, reaching to be picked up, and pointing with vocalization) by the age of twelve months. Formal gestures or signs and pointing to pictures to indicate needs, wants, and simple ideas can be encouraged by eighteen months. Ideally, the program would include all aspects of communication-gestures, pictures, vocalization, and some word approximations. The goal is to enable the child to use the most complete communication system available for expression.

### **Creating a Learning Environment**

Tube-fed children often experience invasive procedures critical to physical survival. They may have felt pushed or forced to eat. As a result, they may erect a series of internal barriers to protect themselves from further invasion. They may discover how important the act of eating by mouth is perceived by others. They learn quickly that adults really want them to eat. Thus, eating becomes a tool in the battle for autonomy, and refusal to eat may become an effective weapon against powerful adults in their environment. The mealtime environment, therefore, must undergo changes to make it more fun. Let us look at how to create a more positive learning environment to support positive eating behaviors.

When spoons or cups are introduced playfully and games are used to make mealtime fun, pressures are reduced. Puppets or dolls create a sense of shared adventure. Explore having the child feed you or another child, their stuffed bear or doll. Have the child play with food, watch the family prepare food, plant a vegetable garden, participate in family meals and even play with pretend food.

The most important challenge that a therapist faces is creating an environment that allows these children to develop trust and an inner knowledge of their own capabilities. This often involves the willingness to acknowledge each child's inner wisdom and to respect the need to progress slowly. Let the child be in charge of the movement when food enters the mouth. Avoid invading the child's mouth by stopping the movement of the spoon about an inch away from the mouth and

letting the child move forward and remove the food from the spoon.

The direct or indirect communication of expectations for oral feeding should be monitored by the therapist and discussed openly with the family. One needs both a belief in the infant's ability to develop and learn oral-motor skills that will result in oral feeding, and a true acceptance of the current status as a nonoral feeder. Infants and children sense both our expectations and demands for success or failure. When parents and therapists are able to accept the child, even if tube feeding continues indefinitely (or forever), any demands that inhibit progress will not interfere with the treatment program. Occasionally the parent or therapist may firmly believe that little can be done for the infant but there is an obligation "to try." This may occur after several months into the program if expectations have been unrealistically high. The child will perceive these underlying feelings of pessimism and discouragement and may attempt to fulfill them. The belief system, then, can result in failure and a confirmation of the underlying negative belief.

The fear of permanent tube-feeding may be accompanied by unspoken feelings that the infant is not acceptable as a nonoral feeder and that the child must change rapidly in the treatment program to win basic love and acceptance. In this case, the child may become discouraged and not make progress because of the conditionality involved in being accepted. When demands are made, counter demands often emerge. A power struggle may develop in which the infant refuses to eat by mouth as a way of controlling the parent and defying the unspoken demand.

The therapist must be willing to release an attachment to results. When the child's progress is linked to feelings of professional and personal worth, creativity becomes lost. Progress appears to be enhanced by an ability to trust an intuitive sense of what the child needs or is ready for at each session. There also must be a trust in the child's inner wisdom, which accepts change and progress as appropriate for each moment. The greatest overall progress in treatment is made when both the parent and therapist are able to accept the child, have a preference and a belief that the child eventually will become an oral feeder, and trust the child's timetable.

When faith in the child's underlying abilities is high, when demands are reduced, and a program that allows for growth is initiated, gains are made.

Music can be used in the learning environment to provide the mutual playfulness and pleasure found in moving and interacting to the rhythm and flow of the melody. Folk music with a clear, regular rhythm and a simple, repeated melody is highly effective with children with severe feeding disorders. Calming background music and music with a tempo of one-beat-per-second enables both the feeder and the child to become entrained to the rhythmical, slow tempo that enhances sensorimotor organization. Music containing the special sound combinations known as Hemi-Sync™ creates a more equal balance of activity in both the right and left hemispheres of the brain and is effective in focusing attention and enhancing learning. Stress is reduced, and both the feeder and child can become open to new possibilities when music is used. The protective barriers, which the child has needed to feel safe, are gradually eliminated, and the child discovers the potential that lies within.

### **How important is timing in the program?**

Although the specific elements of a program are important, the most critical aspect is the timing in which each component is introduced and emphasized. Each child and family is unique, and generalizations may be dangerous. However, the following observations apply to a large number of different children.

The underlying medical problem influencing feeding must be treated. It is difficult, for example, to convince children that eating is fun when they feel pain or discomfort during or after a meal. The feeding therapist can be a link in the medical management of the feeding difficulties. The most basic underlying elements of function or dysfunction should receive the greatest emphasis in the program. For example, if the child has a severe cardiac condition, it must be remediated before the child will have enough energy to eat. If there are severe difficulties with pharyngeal airway maintenance, these must be dealt with before

one can expect there to be a functional suckle-swallow response. If there is gastroesophageal reflux, it must be treated to optimize physical comfort before the child can develop an increased interest in feeding. If there are problems with hypersensitivity or hyposensitivity, therapists can help normalize the child's response to sensory information. If the child is emotionally fearful of feeding, adults must endeavor to make the mealtime and feeding experience safe and pleasant. When fear is present, learning will be compromised. If this underlying prerequisite is not given an initial priority, the child cannot utilize and integrate sensory information and develop new motor responses.

The therapist must have a clear sense of components of sensory and motor development and must skillfully analyze the child's abilities and deficits. All treatment must be done within the framework of a whole child within a whole family. Initial goals will be directed toward building the underlying skills and abilities that form the foundation for higher-level feeding skills.

Specific activities should be built on the child and family's current interests and abilities. Children and adults learn most efficiently when they are allowed to use their strengths and individual learning styles. There are no techniques for improving respiratory and oral-motor skills that can be applied to all children or utilized by all families. The technique becomes an idea for obtaining improved function in a specific area. In the hands of a creative therapist, the technique becomes a theme with infinite variations. These variations emerge from the uniqueness of each child, family and therapist. An observation that the child enjoys the bathtub or water play in a basin may lead to the introduction of a spoon or syringe to stir the water, using a sponge for water play around the face, and letting drops of water enter the mouth on bathtub toys. The child may incorporate the oral stimulation and early swallowing of water in this environment because it is familiar, fun, and non-threatening. The same procedures presented in a mealtime context could be rejected immediately because of previous associations with fear and failure.

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