

# CHILDREN WITH FEEDING TUBES

## Part 3: MAKING THE TRANSITION TO ORAL FEEDING

### When is a child ready to transition to oral feeding?

It is important to remember that there is a continuum from non-oral feeding to oral feeding. It is rarely an “either-or” situation, but is a process. There is a great deal of variation in how children and families respond to tube feeding and the transition journey towards oral feeding. Some children require total tube-feedings with no oral-feedings. Some progress to taking small snacks orally. Some children can eat solids but receive all liquids by tube because of the risk of aspiration. Some children eat by mouth but need extra calories by tube to grow. Other children move to oral feeding demonstrating the ability to grow and thrive without the tube. Where children begin and how they move on this continuum depends on many factors. Long-term difficulties in moving toward oral feeding are rarely caused by a single factor, but rather by a complex mixture of factors. In a comprehensive oral treatment program, the child directs the approach. Therapy can provide experiences and opportunities, but the child will let us know how fast to travel and what direction to go on this journey.

### Are there specific readiness factors that should be considered?

There are a number of factors that must be considered when any transition towards oral feeding is contemplated. These will influence when the child is ready to take a greater variety of foods in larger amounts.

#### Resolution of the Original Problems

We must know whether the medical conditions that led to tube feeding in the first place are resolved. If, for example, the child had the tube placed due to aspiration, is that still present? If fatigue required supplemental feedings due to a cardiac problem, has the cardiac condition been resolved? Did the necessary surgeries occur? If these original conditions continue to be a problem for the child, an active focus on transitioning to oral feeding is usually inappropriate.

#### Overall Health of the Child

The transition toward oral feeding typically involves some reduction in tube-feedings. The assumption is

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made that the child will begin to feel hunger and will make up the difference in calories by eating more orally. However, this may not happen immediately. Even when children are ready for this step, it may take time for the child to understand what is happening and increase oral intake. If children are unwell, they may respond by getting ill or by losing too much weight. When they are not feeling well, they may lack the internal drive and motivation to move toward oral feeding. Thus before moving toward a tube-weaning program we must ask many health-related questions. The child should be in good health over an extended period of time with good growth patterns on tube feedings.

### **Swallowing Safety**

Many children are initially given feeding tubes because they could not swallow safely. They aspirated food or liquid or were at high risk for aspiration. As their prerequisite skills for oral feeding improve, their ability to swallow safely often improves as well. They begin to eat small amounts with good coordination and without any external signs that they are aspirating. This, however, is quite different from taking full meals orally. Some children can handle small amounts of food and liquid, even with some aspiration, safely. These same children may be silent aspirators or may become more uncoordinated and lose their margin of swallowing safety when they must take larger amounts or eat for longer periods of time. If there has been any prior history of aspiration or a videofluoroscopic swallow study that showed risk of aspiration, the swallow study should be repeated before encouraging larger amounts and varieties of food or liquid. Even if the child has not had a history of swallowing difficulties it may be appropriate to refer for a videofluoroscopic swallowing study when larger amounts of food are offered.

### **Status of Oral Skills**

Clearly the child's oral skills play a major role in determining readiness to transition to oral feeding. When they are limited or cannot be sustained over a period of 30-45 minutes, children often resist moving into prolonged periods of oral feeding.

### **Hunger**

Hunger provides the internal regulation for eating orally. Many tube-fed children have missed the gastrointestinal experiences that create contrasting sensations of hunger and satiation. Before moving toward larger amounts of food and weaning from the tube the child should be able to take bolus tube feedings comfortably. These should be given on a feeding schedule of three larger meals and two smaller snack meals. The child should have an initial sense of hunger and the awareness that the mouth and food eaten orally play a major role in reducing hunger.

### **Child Readiness**

Children progress toward oral feeding when they are interested in this way of taking in food and when they are ready. Readiness is an internal phenomenon. Adults can provide the encouragement and introduce children to the experiences that seem to promote readiness. However, readiness itself is perceived and directed by children, not by adults. It is important for therapists and parents to look for and encourage any signs that the child is interested in food and in eating. Interaction with foods and liquids stimulates enjoyment and involvement. Children usually reach for food or the spoon and try to put them in the mouth. Some children are not interested in eating because they do not feel well or experience the discomfort of gastroesophageal reflux or retching every time they eat orally or by tube. Often the parent or therapist wants the child to eat orally when the child has very little internal interest in eating.

### **Parent Readiness**

Helping a child make the transition from tube feeding to oral feeding takes time and commitment from parents. It is important to know whether the parent really is ready for their child to move towards oral feeding. Parents become the team leaders in this process. Much of the effort will rest on their shoulders. They need to understand all of the issues involved in transitioning the child to oral feedings and have the patience to let the child lead the pace toward eating.

## **What progressions are used to move children toward oral feedings?**

### **From Non-Foods to Foods**

Moving from non-food to food situations must be done slowly and with respect for the child's needs and abilities. At first, a taste may be presented on the finger or in drops of water. The intensity of the taste or the quantity of liquid is gradually increased, the child's response is observed carefully, and additional challenges are provided only when the child shows readiness. A wide exploration of taste, and texture should continue to be combined with extensive oral play. Small drops of liquid are similar in taste and amount to the saliva that a child may already be able to swallow successfully. When it is gradually introduced with mouth play to develop tongue and lip movement, it may be swallowed with relative ease. Gradually working progressively with cotton swabs, a medicine dropper, a small syringe, an infant spoon, and a cup can increase the amount. Liquid, however, may pose a major problem for infants and children who have substantial difficulties in coordinating breathing and swallowing. Some children need to start with a pureed consistency.

Pureed foods appear to be easier for some children who need stronger sensory cues of weight, texture, and taste in order to organize the sensorimotor response in moving the food to the back of the mouth. The slightly thicker, heavier consistency doesn't flow out of control as rapidly as does liquid. Because of the slightly greater time and control allowed by the thicker food or a thickened liquid, the suckle-swallow is improved. Other children appear to need the consistency of the semi-solid foods followed by drops of liquid to clear the back of the tongue and pharynx.

The child should continue to enjoy the taste and texture transition to purees if they are presented carefully. There is a tendency for infants to stop the rhythmical tongue movements and revert to old patterns when food is initially introduced by spoon. Panic, disorganized mouth movements, and protective tongue retraction may occur. In some situations, the child has had previous negative experiences with the spoon that can trigger fear and protective responses. Consider

introducing the purees on the child's finger, a familiar mouth toy or pacifier. It is critical that the emphasis be placed on sustaining a rhythmical suckle movement of the tongue. If this is lost, the amount of food presented on the tongue should be reduced or the food thinned down until the rhythmical movement returns. When the child becomes fearful, old patterns of head extension, body arching and overall incoordination may appear, increasing the risk of choking and aspiration.

Children will show their preferences in how they make taste and texture transitions. Some prefer strong flavors, and some prefer diluted. Some prefer to move from tiny amounts of thin liquids to larger amounts of the liquid. They may then move toward nectar consistencies and then expand their skills with different feeding utensils such as a bottle, cup or straw. Others move from liquid tastes to purees and gradually on to solid foods. Still others quickly leap from liquid tastes to crumbs and "meltable foods" then on to more challenging solids, refusing any offerings of wet foods. Children show their preferences and let us know their readiness for new challenges.

### **Feeding Utensils**

Parents often ask whether an infant should be placed on the bottle or breast if initial feeding difficulties required that tube-feedings be given. Much depends on the strengths, specific problems, and age of the baby. If a rhythmical sucking pattern is present and tongue retraction does not increase when the nipple is inserted, feeding from the bottle or breast may be a realistic goal. A rhythmical suckle on a finger or on a thin cloth or sponge dipped in water, breast milk or formula can prepare the infant for bottle- or breast-feeding. The Hazelbaker™ FingerFeeder\* can be used to feed the baby off the adult finger. A soft preemie nipple may be used to obtain an easier suck. If the infant is able to continue a rhythmical suck- swallow without excessive liquid loss or choking, a juice nipple with a slightly larger hole, a Haberman™ feeder\* or a Supplemental Nursing System\* for breast-feeding, may be used.

Many babies move directly to cup drinking bypassing the nursing or bottle- feeding stage. The age of the

child and the severity of the oral-motor difficulties will influence the decision. Some babies have severe sensitivities to the touch of the nipple in the mouth. Some become disorganized with the presentation of the nipple with resulting tongue retraction or disorganized movement. Some infants are not able to maintain the energy level and organization need for nipple feeding. Cup drinking for these children can be more appropriate.

Still other babies and young children show their greatest eating skills with the spoon. Especially when they learn to use an active movement of the lips to draw food into the mouth from the spoon, they seem able to control the amount and movement of food or liquid more efficiently. These children may bypass the bottle, breast and cup stages initially and take all of solid foods and a small amount of liquids from the spoon. They may continue to receive larger amounts of liquid by tube until they have developed the ability to coordinate their sucking-swallowing-breathing pattern for a larger volume of thin or thick liquids.

### **Mealtime Modeling**

When there are strong signs that a child may be developing greater interest in eating and moving towards oral feeding, the child must move from the lap, floor or bed to the family table for tube-feeding during regular mealtimes. This step can be built into the initial stages of the program for most children. It builds an association between the satiation of hunger provided by the tube-feedings and the sights and smells of a regular meal within the social context of a family mealtime. The child may be given spoons, bowls, or food on the tray to encourage feeding play. Children who show interest in tastes can be given food and liquid to taste during the family mealtime. The emphasis is on the positive mealtime experience and mealtime imitation rather than on the quantity of food.

### **Dietary Preparations for Oral Feedings**

Dietary support should parallel efforts to prepare the mouth for oral feeding. Increasing nutritional variation in the tube diet may help prepare the child's mouth, nose and gastrointestinal system for new foods. When only formula is given by tube and cereal, fruit, vegetables, and juices are only offered orally, problems

can develop. Children with a genetic predisposition toward allergy may develop allergic triggers from repeated challenges of the food sources in a formula that is given at every meal. These children may develop allergic or hypersensitive reactions to new foods that are offered by mouth. These reactions can trigger increased mucus, abdominal discomfort or pain, headache, or feelings of irritability and unwellness. The child may associate the oral feedings with discomfort and refuse to eat. If individual foods are pureed and diluted with water and given occasionally by tube, allergic or hypersensitive responses can be identified before the child has experienced them orally.

If the child has high caloric needs and is able to take only tube-feedings, it may be difficult to provide adequate non-formula calories in a volume that can be tolerated by tube. In that case, non-formula meals via the tube may be deferred until stomach capacity is greater and a larger diameter tube can be inserted, which would require less dilution of the food. However, mini-meals of different foods can be given by tube and the child's reaction can be observed. Because of the immature digestive system, pureed foods should not be given before an infant is 4-months old. When they are added by tube, new foods should be added at three- or four-day intervals in the same way new foods are added by mouth in the typically developing infant. Consult the child's physician or a dietitian to determine the best diet when the child is ready to begin the transition to oral foods.

Both learning to enjoy new foods and a healthy diet are extremely important in helping children move from tube-feedings to oral-feedings. It is very easy to get into the trap of giving children only sweet tastes and junk foods because they may be more interested in these foods. In our experience this can become a big trap. Children continue to be drawn to the types of food that we give them as they are learning to eat. If we really want children to be capable of supporting their body's nutritional needs orally, we need to think in terms of healthy foods and dietary diversity from the very beginning. The focus in therapy should help them learn to accept and enjoy small tastes of a wide variety of foods. This focus should not emphasize increasing the amount of one or two foods. It is

important to begin with the types of taste that are easiest for the child, but therapists and parents must help the child move toward new foods and new tastes from the very beginning. For some children this may be simply changing the brand of food so that the change is very small. However the overall goal is to develop a wide variety of tastes that the child will like and accept. It often is hard for families to develop a long-range view when they want their child to eat now. But it is really worth it in the end. We can start with the small steps in the beginning that take us to what we really want— children who are happy, comfortable and well-nourished as oral-feeders.

### **Hunger as an Ally**

A successful transition to oral feeding depends on the child's association of oral-feeding with hunger and its reduction, and on the child's physical ability to take some food orally. In preparation for the transition to oral feedings, the tube-feeding schedule can be modified to promote both hunger and a more normal mealtime routine. Hunger can and should be used as an ally in encouraging the child to take more by mouth. Tube-feedings can be adjusted so that their volume and timing is similar to an oral feeding pattern of three large meals and two smaller snack meals per day. When smaller, more frequent tube-feedings are given or a continuous drip-feeding pattern is used, children never feel the sensations of hunger or satiation. Their system is totally unprepared for the internal cues that create the needed motivation to accept oral-feedings. Some children have been fed all of their calories by continuous drip feedings at night. Parents and professionals hope that they will be hungrier during the day. This works for some children but not for others. Some children have been tube-fed for so long on such a schedule that they do not identify hunger at all. A daytime bolus-feeding schedule may more readily provide the child with the contrasting sensations of satiation and hunger that can be more easily associated with food and eating.

When a hunger/satiation pattern has been established, parents should identify the time of day when the child's energy level is the highest and mood is the best. Most parents notice that some meals are consistently better for their child. They can identify when the child

seems hungry and most willing to take on the challenge of an oral meal.

Once the child shows interest and skill in eating foods and the parents can identify optimum times for mealtime challenges, hunger can be used creatively to enhance the child's motivation in eating. There are many ways to rearrange the feeding schedule and the calories. The decisions may depend on the child's hunger, interest in foods, and stomach capacity. It also depends on the family routine. The child's growth, nutrition, and fluid needs must be closely watched. The physician or dietitian usually works closely with the family and feeding therapist during this transition.

A time limit of fifteen to thirty minutes should be set for oral feedings. During this period, during which the child is allowed to eat as much as desired. The remainder of the meal then would be given by tube. The child should enjoy the social interactions, mealtime conversations and mealtime atmosphere. There should be encouragement and support without coercion, force or pressure to eat. The parents need to know that the tube is still there as a nutritional support. Whatever the child does not take by mouth can easily be given by tube.

Too many transitions to oral feeding bog down at this point as prematurely enthusiastic parents and therapists put direct or indirect pressure on the child to eat more. If calories are decreased too drastically early in the weaning process, stress will increase and the program can fail. Parents want their children to remain healthy and not lose weight. A rapid reduction in calories can put too much pressure on the parents to "help" the child take in enough food. This, in turn, can put pressure on the child to eat more than is comfortable. Weaning a child from a feeding tube is a process, not an end destination. It can often be a slow process. The tube is there to help until the child is very capable and willing to take in sufficient food by mouth. Parents and therapist must listen to the child and let the child set the pace. Health, good growth, and positive mealtime experiences are the most important goals.

### **Removing the Feeding Tube**

An indwelling feeding tube (e.g. gastrostomy tube) should remain in place following a complete transition to oral feedings. Oral-feedings should become fully stabilized and the child's needs for liquids and solids should be satisfied orally even in time of illness before the tube is removed and the insertion closed. The premature removal of the tube may create excessively long meals for the child and feeder and may introduce the possibility of malnutrition or failure to thrive, especially during times of illness.

### **What is the role of maturation?**

Time and maturation can be important allies for many infants in developing better feeding patterns. This is primarily related to changes in anatomical structures and reduction of primary respiratory problems that occur during the first year of life. When feeding difficulties are increased by a disproportionately small jaw or by difficulty in maintaining the size of the pharyngeal airway (as in micrognathia or Pierre Robin Syndrome), anatomical changes will occur over time. The downward and forward growth of the mandible and the elongation of the pharynx, which begin at four to six months can play a positive role. These anatomical changes increase the pharyngeal airspace for breathing and provide a larger oral area for tongue movement, thus reducing stress on the respiratory and feeding systems. Poor health related to respiratory or cardiac difficulties may be reduced as the infant matures. With greater ease of breathing and greater energy, progress in oral feeding may become easier.

The contribution of time and maturation to the process does not mean that referral for treatment and an intervention program should not begin during the first year. Emphasis during the initial stage of treatment should be placed on developing postural control, on communication and interaction during nonoral feedings, on normalization of oral sensitivity, and on oral exploration.

### **What is the role of change?**

The role of change in human behavior is important to recall when working with young children. As the infant matures, the sensory feedback from the restrictive, nonfeeding patterns becomes familiar and is incorporated into the developing body image and self-concept. When change becomes possible through therapeutic handling and stimulation, it is unfamiliar and may be frightening. There is a tendency to cling to the old pattern. This is particularly true when the habitual pattern included compensations that enhanced survival. Thus, a child who choked during swallowing may find it difficult to use a suckling response to draw liquid into the pharynx. Another child may resist swallowing semi-solid foods, knowing that swallowing produced a sense of suffocation at a time when respiratory abilities were stressed by oral feeding. These old habits and perceptions must be acknowledged, and the therapist must resist pushing the child into new behaviors. The therapist is a guide who introduces new possibilities. The child is encouraged to explore these new ways of being. If the changes are presented as something new and interesting, they may be accepted when the child is ready because there is no battle and no image to be preserved. Therapists frequently strive for repeated gains and changes without pause. This often pushes the infant or child to the point where there may be a functional retreat into less mature but familiar behaviors. Natural plateaus must be allowed and encouraged. The child needs these pauses to stabilize a newly learned behavior before moving on.