

Recommended Reading

Tube Feeding Transition Plateaus

By Marsha Dunn Klein MEd. OTR/L

Article from *EP Exceptional Parent* magazine, February 2007 Vol. 36 Issue 02

The journey children make from tube feeding to oral feeding is personal for each child and family. However, there are some predictable plateaus that children reach in this transition. Understanding the transition plateaus and the reason children spend time on them can help professionals to better support parents and children in this process.

Many tube transitions focus on the number of bites the child takes by mouth or the number of calories eaten at each meal. Though the goal is to help the child take in more oral calories as tube calories decrease, the more narrowed focus on counting bites can be a lot of pressure on the child and the family. The child may take bites at the expense of enjoyment in the mealtime process. Parents may count bites eaten but feel stressed about the number of bites not eaten. Children can feel this pressure and this disappointment, making the process harder.

The Plateau Approach

For more successes and less disappointment, look past the bite-by-bite approach and view the big picture. There is a sequence of predictable plateaus that children climb as they move toward orally eating. By understanding this sequence, parents and children can maximize the development, learning, enjoyment and confidence at each plateau.

A plateau is a step in the transition from tube feeding to oral feeding where a child needs to spend some extra time. For some, it is weeks or months, and for others, it can be years. The amount of time is unique for each child and family. Children move from one plateau to another but need time to practice and build confidence at each level BEFORE moving to the next level.

We see these same plateaus with orally fed children. They move from breast or bottle to purees and to solids. But parents don't introduce a puree one day and then start counting the bites, changing the texture and reducing the liquid intake immediately to make them hungry! We give them time to practice and enjoy each level. We take our cues from them as to readiness for new foods and new challenges.

It is the same with tube fed children. They move through identifiable steps, going to next levels at their own pace.

Trust, The First Plateau

The first plateau forms the very foundation of transitions to oral feeding. Many children who are tube fed have had multiple medical procedures around the face. Ventilators, nose and mouth tubes leave many infants worried about ANY touch around the mouth and face. This cautiousness combined with inexperience with oral eating causes many children to gag, vomit and defend themselves from ANY touch around the

mouth. Before the child can become friendly with food texture or taste presentation, they must learn to enjoy touch around the face. If the child is not even comfortable with kisses, hugs and mouthing his own fingers, how can he be comfortable with nipples, spoons or food?

In the first plateau, parents offer opportunities for the child to trust the sensations of touch around the face. Parents provide kisses, hugs and massage that are loving, tender and predictable so the child learns not all touch is scary. The child gives permission to get closer to his mouth as he snuggles into the touch, gradually pushing away, gagging less and enjoying more. If the child gags when the cheeks are kissed, parents can start in friendlier territory like hands, arms, shoulders, or neck and move toward the mouth. Parents can help children discover their own fingers and toes. They can create playful games and songs where touch to the face is part of the interaction. A puppet can kiss up a child's arms to the face. A stuffed toy can nibble on the child's nose. A cloth can be playfully removed from the child's face in a game of "peek-a-boo". The secret to success in each of these activities is to be tender and predictable.

The goal of this plateau is for a child to trust kisses and touch around the face and comfortably bring fingers to the mouth. By the end of this plateau, the child initiates these mouth play activities and can enjoy them enthusiastically.

Exploration Plateau

To become oral eaters, children need to become comfortable with food. Comfort with food comes from interaction with it and not just eating it. Parents often hand food to a child and say, "try it" meaning "put it in your mouth and eat it." For many cautious children this is entirely too scary and if the parent insists, it may undermine the trust that was gained on the last plateau. "Try it" may need to be redefined as being near it, smelling it, touching it, handing it to others, putting it in the mouth and then spitting it out, and, finally, putting it in the mouth and chewing and swallowing it. Adults create an environment where any type of "trying it" is celebrated.

In Exploration Plateau parents offer opportunities for the child to explore by mouth by providing toys of different, soft, friendly and "mouthable" textures. Once the child enjoys mouthing, the medical team will determine if it is safe to introduce food tastes.

Adults can then offer a variety of tastes on the child's fingers and familiar toys. Fingers and toys can be dipped in milk, juice, broth or a tiny amount of puree. Adults can creatively offer a variety of tastes and textures watching carefully which ones the child enjoys enough to try again.

The goal of the Exploration Plateau is for the child to become comfortable interacting with foods and textures, but the child is not yet taking quantity. It is not yet time to count bites!

Confidence and Variation Plateau

Parents help children develop confidence and food enjoyment during this next plateau by providing opportunities to interact with food in many different ways.

Start by offering familiar foods the child enjoys. Make changes from that safe base. These changes can be with the food itself or the presentation of the food.

The child who likes yogurt may be offered it off a regular spoon, a large spoon, the wrong end of a spoon, a fork, a toy, a finger, a cookie or even an apple slice. Guacamole can be eaten off a cracker, chip or pretzel. Soup can be tried from a spoon, a straw, a cup, or used as a dip and enjoyed off a carrot stick, piece of cooked broccoli, or zucchini. Wet foods can become dips. Dry foods can become dippers. Crumbs can be added to the top of the spoonful, under the spoon, or in the mixture. If the child likes the texture of yogurt, other wet and smooth foods can be offered.

Food timing is important. Oral foods should be offered while the child receives the tube meal so he can develop a positive association between a filled tummy and oral foods. For so many children, this relationship has never developed, or the child may have a negative relationship with food that has made them sick or uncomfortable. During this Confidence and Variation Plateau, children begin seeing themselves as oral eaters and part of family mealtimes!

Parents can offer enjoyable mealtime experiences that don't just focus on actual eating. Older children can participate in meal preparation. They can help bake cookies or make blender drinks. They can add foods to a salad or spread butter on a cracker. When the focus is on the interaction with the food, comfort increases and gradually there will be enough familiarity to try it. As children become older, they proudly participate in serving food, handing food to others and setting or clearing the table. This gives the child opportunities to participate in mealtimes in positive ways while learning to be comfortable with food intake.

Confidence and enjoyment are also developed when the skills of mealtimes are mastered—successes with spoons and forks, cups and straws, and successes with wet, dry, thick and thin foods. Variation is developed as the child learns to control different size cups or straws, and foods of different flavor, texture and quantity.

Children should learn to enjoy four or five foods in every food group. When they eat a variety of foods, parents are more confident in the child's nutrition and feel less pressure later as the tube feeding calories are decreased. Too many transitions to oral eating become very complicated when the child just likes only one or two foods, and, all of a sudden, the team takes away calories. Why would a child who has just become comfortable with yogurt suddenly eat a balanced diet if calories are reduced?

In the Confidence and Variation Plateau children learn to enjoy and be confident eating a variety of foods and mastering the skills of eating and drinking without the pressure of calorie reduction.

Explore Appetite

Another important part of this plateau is exploring the child's ability to respond to appetite. For parents to consider tube removal, they need to be confident that the child feels hunger and is internally motivated to eat. Up to now, the child has eaten in imitation of others as a social response, not as a hunger response. But when the tube is finally removed, the motivation for adequate intake needs to come from within the child, an internal motivation, not just to please adults or in response to adult pressure. If the tube is removed without achievement of internal motivation, taking in enough food at each meal continues to be the parent responsibility. Pressure continues. No one feels good about this pressure.

Exploratory Appetite Challenges offered during the Confidence and Variation Plateau allow parents to explore the child's hunger WITHOUT reducing calories. Tube feedings are ideally offered in bolus "meals" at regular intervals or at "mealtimes" during the day to simulate a typical oral eating schedule. Many children need some additional food by drip at night because of the difficulty taking in enough volume in the daytime alone.

The idea is to simulate a routine appetite cycle of hunger and fullness to help the child's body identify these feelings. For example, the child may be offered 6-ounce boluses at 8am, 12pm, 4pm, and 8pm. Once the child becomes used to this routine, one feeding "re-arranged" in an Exploratory Appetite Challenge. For example, the 12:00pm, feeding may be offered at 1:00pm. Oral foods are offered before the bolus. The goal is to explore if the child demonstrates signs of hunger by reaching or asking for food, trying new foods or increasing the oral intake in response to this challenge.

Appetite challenges have a beginning and an end and last a set number of days. Open-ended challenges tend to cause too much stress for everyone involved and decrease the "exploratory" focus of this challenge. After a three day or seven day duration, the challenge is done and then the parents see what was learned. How did it work? Did the child try a new food?

The family returns to the old routine again and later may try a new challenge. Perhaps only half of one feeding is given by tube and then replaced at the end of the day. Perhaps a feeding is removed entirely and put at the end of the day. Perhaps a different mealtime is adjusted. Since no calories are removed from the 24-hour feeding schedule in Exploratory Appetite Challenges, the child doesn't lose weight, parents aren't stressed and child and parents have the opportunity to better understand the child's hunger.

It is hoped that during the Confidence and Variation Plateau, there would be many opportunities for Exploratory Appetite Challenges as the child is feeling good, gradually increasing confidence and mastery of eating skills and identifying a consistent eating response to hunger. Though oral intake certainly increases during this stage, it's still not time to "count bites". Instead, it's time to celebrate moments of enjoyment, responses to hunger, and skills mastered.

Quantity and Hunger Plateau - The Last Plateau

The last plateau is the Quantity and Hunger Plateau. By the time the child moves to this plateau, he's enjoying a variety of foods, feels well, has the eating skills necessary for success and responds to hunger with increased eating. The child is orally eating good quantities of food and drinks and feels like an active and celebrated part of the family mealtime. He has confidence in his mealtime skills and parents are confident that he is growing well and is internally motivated to eat.

The focus of this final plateau is the gradual reduction of tube calories as oral calories increase. Parents need to have support in place from the pediatrician, dietitian and feeding team whenever calories are reduced in order to monitor growth, weight and hydration. The child MUST be well, have steady growth, and physically ready to consider moving towards tube removal.

Finally, it is time to try Calorie Reduction Appetite Challenges where the amount of calories in the day is reduced in some fashion. Once again these challenges have a beginning and an end. The feeding team decides on a reduction amount and then tries it

for a defined period of time depending on the child's health and skills. The challenge is created conservatively so everyone involved feels the child will succeed. It should not be an open-ended "hope-he-doesn't-lose-too-much-weight" approach. This stresses everyone. There also needs to be time for assessment. Was the child ready? Did the child comfortably take in more oral calories? Did weight stay steady?

A Calorie Reduction Appetite Challenge could reduce one ounce from one tube meal, or four ounces from a meal or one hour of drip-feeding at night. An entire feeding may be removed. They are designed creatively, depending on the child. The child's intake and weight are monitored to see that the child eats more calories per day as tube calories are reduced.

If the challenge has been picked well, everyone is comfortable and little by little more tube calories can be removed. If the child and parents are stressed, the reduction was probably too great and everyone wasn't yet ready. Go back to the regular routine and then try again later.

Parents have spent so much time with Exploratory Appetite Challenges by the last plateau that they are fairly certain of success. Children may experience many little appetite challenges during this plateau, over months. If they have skills, enjoyment and good health calorie reduction becomes a calm natural progression that's created for success.

The speed with which a child moves through the Tube Feeding Transition Plateaus and his success with appetite challenges is individualized, depending on the child's growth, how well he feels, the degree of cautiousness and the length of tube placement. Of course, no transitions to food can be considered without medical approval and swallowing safety! The journey is influenced by the relationship between the parent and child and the level of trust that can be developed around food. Parents are encouraged to use the tube to optimally nourish the child and help him grow while taking the time necessary to develop trust, enjoyment, confidence and skills for oral eating.