

# **Tube Feeding Terminology: The Power of the Words We Use**

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The words we use reflect our attitudes. The terminology used in tube transitions is very important. Let us think about the words we use when we offer tube feedings to children.

## **"Mealtimes"**

Some of the terms used in provision of nutrition by tube are "boluses", "drip feeding", "pump feedings", "doses", "procedures", and "tube feedings". We would like to help families think of tube feedings as mealtimes, too. How can we help the tube feedings turn into mealtimes with all the social, emotional, communication and nutritional variations?

"Feeding" sounds like something done TO a child. As orally fed children get older, we no longer use the term feeding, as they are more able to actively participate in the mealtime process. Can we more actively involve tube fed children in the mealtime? We would like to look at the tube nutrition as a partnership WITH the child, following the child's pace and comfort level. Can we substitute the term "mealtime" or "meal" for "feeding"?

How might our interactions with the tubes change if we call the tube nutrition "meals", "breakfast", "snack", "lunch" or "dinner"? How about "tube meal" or an "oral meal"? Or a "tummy meal" or "mouth meal"? Or "tummy snack" or "mouth snack"? We want to think about vocabulary that works within each family, but that celebrates the mealtime and inclusion of the child who receives nourishment by tube, and not the differences and separateness.

## **Sensory "enjoyment" not "tolerance"**

We see many goals for tube fed children as they learn to eat foods orally that describe "tolerance" of a certain texture or flavor of food. Would we make goals for ourselves to "tolerate" mushrooms or "tolerate" calves liver? If a giant grown up person forced us to eat a food that we did not like, or that made us feel sick, would be happy with "tolerate"? Would it help us like that calves liver any more? "Tolerance" implies that it was an adult decision for the food to be eaten. Enjoyment implies that it was a child decision.

If we look for "enjoyment" we look at food introduction as a slower process lead by the pace that is comfortable for the child. The child let's us know what she likes and what she wants try again. She let's us know what foods are enjoyed and we

build from there. Many families tell us it feels better to celebrate a list of "enjoyed" foods rather than "tolerated foods".

### **Bites**

We do not count numbers of "bites" with orally fed children. We offer, and then allow them to eat what they can and what they want of what we offer. How did the balance change for tube fed children where we consider a "meal" to be a required number of bites? When we count bites, the meal becomes the adult's idea and the child is often "tolerating" the situation (or not)!. If we think of the adult role to offer food creatively and the sensitive child's role to give permission for what is comfortable, what is enjoyed, the meal becomes about enjoyment and not a predetermined number of bites.

### **Confidence**

Many tube fed or sensory challenged children not only have difficulty with sensory enjoyment but also with confidence in the oral motor skills of eating. They often are taught to eat in a certain chair, from a certain spoon, and from a certain cup. Caring adults find something that "works" and then repeat and repeat the same scenario. But, if we look at how orally fed children move from breast and bottle to solids, we know that they have lots of experiences eating from laps, infant seats, high chairs, and boosters. They put lots of different textures in their mouths as they mouth fingers, toes, toys and bibs! They are fed from baby spoons, regular spoons, parents' fingers. They become used to these different textures and confident with their mouth abilities and the different textures of mealtimes.

Sensory careful children who are repeatedly offered the same textures from the same spoons seem to be slower at developing confidence. How about if we offer tastes they enjoy from different places so they learn to control their mouths in different postural situations? How about if we offer food they enjoy from different "spoons". We can be creative with what we mean as "spoons". "Spoons" can be baby's fingers, parent fingers, soft spoons, or soft or hard textured spoons, textured mouthing toy or textured therapy tool. For variation they can also be the right end of the spoon, or the wrong end of a spoon, a wooden spoon, or a spatula, all commonly found in the kitchen. Children develop confidence as they enjoy the food or flavor offered and they adapt their mouth to the shape of the incoming spoon. Fingers and toys brought to the mouth by children enter in the front, at the sides of the mouth, at the corners of the lips and at the center. They enter in the front of the mouth and too far back. Each experience allows the child to adapt and adjust so the mouth learns to respond to different shapes. This is the beginning of oral perceptual skill development and helps confidence.

### **Internal motivation not external motivation**

When children have sensory mealtime challenges, the balance of eating motivation often shifts from child directed "internal motivation" to adult directed "external motivation". Children who are independent eaters and who grow well without interference from the adults are internally motivated. They eat what they can of what is offered and know when they have had enough. An extreme example of external motivation would be a situation where the child is force fed or where the child is uncomfortable with eating and demonstrates the discomfort while still being fed. This child may only eat orally because an adult is "making them", coercing them, bribing them. In the long run, the child is not learning to listen to his own internal cues. He is not learning that his wishes at the mealtime are heard. He is learning to give in, to tolerate the food. External motivation may become tolerated, but internal motivation becomes enjoyed.

By carefully considering our words and the meaning of those words we may be able to more sensitively help tube fed children make the transitions from tube feedings to mealtimes, enjoyment, confidence and internal motivation.