

Feeding Issues in Individuals with CdLS: What Should We Be Considering?

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Many people with CdLS experience feeding issues at some point in their lives. Health concerns, anatomic and physiologic differences, and sensory issues can impact the ability and desire to eat. A history of tube feeding; gastroesophageal reflux disease (GERD); esophagitis; low muscle tone in and around the mouth; a small jaw (micrognathia); a high, arched palate (roof of the mouth); a cleft palate; side effects of medications; food allergies; oral defensiveness; and aspiration of food or liquids can make oral feeding challenging and undesirable for an affected individual.

Among individuals with CdLS, oral feeding challenges can include food aversions; eating limited varieties of food; consuming small amounts of food during meals; taking very tiny bites; eating very slowly; spitting food out; being a messy or picky eater; and even refusing to eat. On occasion, however, some individuals may “stuff” food in their mouths and food may collect at the roof of the mouth. Symptoms of oral feeding difficulties include choking, coughing, gagging, vomiting, a “gargly” sounding voice after feeding, aspiration (food or liquid enters the lungs, which can lead to pneumonia), and food aversions.

In infancy, children with CdLS may exhibit difficulty sucking or coordinating sucking, swallowing and breathing. Some difficulties may not be observed until infants are a few months old, when anatomical changes in the mouth and neck, as well as shifts in body positioning during feeding, may make it difficult to control food to swallow it safely. During early infancy, the tongue fills the mouth and the cheeks have sucking pads. These offer stability during feeding. In addition, the epiglottis protects the airway. With this type of anatomy, it is easier to control liquids in the mouth, and babies can swallow and breathe at the same time, reducing the likelihood of choking. During infancy, babies begin to lose liquids from the sides of their mouths as the natural body position moves from a primarily flexed position (elbows and knees bent) to a more extended position (arms and legs straighter). The muscle tone of infants in the flexed position helps them to keep from losing liquids from the sides of their mouths. As they moved to a more extended position, some loss of liquids from the sides of the mouth may occur.



Around 3 to 4 months of age, the neck grows, and the epiglottis no longer is in the same position as it was earlier in infancy, so it loses its protective function. Infants who previously did not choke during feeding may start to do so at this time because of the changes in their bodies and the need to coordinate feeding and swallowing with breathing.

Around 4 to 6 months of age, when the mouth is growing, infants' tongues and cheeks have to learn to better control food in the mouth because the sucking pads are diminishing and there is greater space in the mouth as the jaw bones grow, preparing for more solid food consistencies. Additional challenges may become present as children move from liquid to solid foods, and their mouths have to learn to manage food that is thicker or needs to be chewed. Children also have to learn to manage multiple consistencies in food, such as yogurt with fruit chunks and the small, soft pieces of vegetables, rice, and pasta in baby food.

If a child has low muscle tone in and around the mouth, this can impact feeding because there may be a lack of strength to bite and chew foods. In addition, because of the extra effort associated with biting and chewing, the child may fatigue easily and not want to continue feeding. When a micrognathia is present, the chin is in a retracted (pulled back) position and the tongue is further back in the mouth. When the tongue is in a more retracted position, the infant's ability to breathe during feeding can be affected, particularly if the infant is fed in a reclining position, where gravity naturally pulls the tongue toward the back of the mouth. This position could potentially block the airway. When micrognathia is present, the relationship between the upper and lower jaw is shifted. Because the lower gums and teeth are in a compromised position, biting and chewing can be more challenging.

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