



CdLS Foundation

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Feeding Issues in Individuals with CdLS

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Many individuals with CdLS experience feeding concerns at some point in their lives. Challenges can include food aversions; being a messy, slow, or picky eater; eating limited varieties and small amounts of food; taking very small bites; spitting food out; and refusing to eat. On occasion, however, some individuals “stuff” food in their mouths.

There are a variety of factors that impact feeding, including gastroesophageal reflux disease (GERD), low muscle tone in and around the mouth, a small jaw (micrognathia), oral defensiveness, and aspiration of food or liquids. Symptoms of oral feeding difficulties include choking, coughing, gagging, vomiting, a “gargly” sounding voice after feeding, aspiration, and food aversions.

Infants with CdLS may have 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 may make it difficult to control food to swallow it safely. Other challenges become present as children move from formula to solid foods.

Approximately 90 percent of individuals with CdLS experience GERD. These symptoms include spitting up or vomiting during or following meals, as well as pain or discomfort associated with feeding. Consequently, individuals affected by GERD may develop feeding aversions. Food aversions also are frequent among individuals with a history of tube feeding. When children are tube fed, the tube feedings bypass the need for oral feeding and can result in a lack of exposure to a variety of tastes, textures, temperatures, smells, and food presentations that provide oral stimulation and make meal times a pleasant, social experience.

In addition, individuals who are tube fed may be fed in places, such as bedrooms, or at times, such as during the night, that are not typically associated with feeding experiences. Thus, it’s essential to provide individuals who are tube fed with opportunities to experience both the oral and social stimulation associated with meals.

Individuals who exhibit feeding challenges should be referred to a speech-language pathologist, and medical clearance should be obtained prior to initiating oral feeding. Individuals with swallowing difficulties, such as coughing, choking, or gagging during meals, typically are recommended for a swallow evaluation. The evaluation will determine whether aspiration, the accidental sucking in of food particles or fluids into the lungs, occurs. If no aspiration is evident, it’s probably safe to feed orally. If there is aspiration, modifications such as thickening of liquids or pureeing of solids may be recommended. Liquids may be thickened with baby cereals, baby foods, oatmeal, flour, corn starch, yogurt, applesauce, and



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commercially available thickeners. Soft pieces of pasta, rice, potatoes, cooked vegetables, and canned fruit may gradually be added to provide textures that are relatively easy to manage. Gradually increase the number of pieces and the firmness of the pieces before moving to firmer foods, such as bread, soft breadsticks, medium cooked vegetables, lunch meats, and fish sticks. Eventually, transition to firm solids, including apples (they may initially need to be peeled or cut into slices), carrots, meats, teething biscuits, crackers, pretzels, granola bars, and so forth. Remember to proceed in small, gradual steps as broader food preferences are encouraged.

No oral feeding should occur unless medical clearance is obtained for individuals with a history of feeding difficulties. If oral feeding is contraindicated, oral stimulation should still be provided, using a variety of tastes (sweet, salty, spicy, sour, bland), textures (smooth, bumpy, soft, firm, “squishy”), and temperatures (warm, room, cool, cold, and frozen).

Taste stimulation can be provided by adding objects to a child’s hands, such as traces of food or liquid, toys, pacifier, toothbrush, cloth baby book, teething ring, and wash cloth, or by putting solid foods in a safety feeder (a small device with a mesh bag attached to a solid plastic ring, available where baby feeding items are sold). To provide temperature stimulation, appropriate items can be placed in the freezer or refrigerator, warmed in the microwave oven or in warm water, and so forth. Texture stimulation should be provided by utilizing items of various textures, such as those described, as well commercially available “chewy tubes” and refrigerator tubing.

Initially introduce only one stimulus (taste, texture or temperature) at a time, if a child has a history of feeding aversions. Once each is reasonably well tolerated, stimuli can be combined, for example, by trying cold applesauce that previously was tolerated at room temperature. Also stimulate the oral area using deep touch. The lips, cheeks, and chin can be strengthened by applying firm pressure and massage. Strengthen the tongue by applying pressure with a finger down the center of the tongue and by gently pulling on the tongue and shaking it, while holding it with a wash cloth. These techniques may also reduce oral defensiveness and lead to better oral feeding skills. Be sure to engage your child in a very playful manner.

Ultimately, every attempt should be made to keep feeding social, enjoyable, and fun.