

CHARGE Syndrome Information: Oral-Motor and Feeding Issues

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Most students with CHARGE syndrome exhibit oral-motor and/feeding issues. These students benefit from therapy with speech and language pathologists (SLP), and occupational therapists (OT) working together. The oral-motor/feeding therapy team may also involve parents, pediatrician, gastroenterologist, nurse, behavior specialist, physical therapist, psychiatrist/psychologist, as well as classroom staff. Consistency of routine and communication among everyone dealing with the child is important.

Due to the complex oral motor/feeding profile of these students, as well as the strong emotional component around mealtime, it is imperative to assess and treat the child as a whole. Because feeding is a multisystem issue, assessment needs to be done with a team of the above-mentioned professionals. Once the medical team has determined that the student can eat orally, an assessment will look at the following: nutritional needs (calories), structure and function of the oral cavity, sensory awareness in the oral cavity, positioning, and ability to tolerate various textures/consistencies/temperatures. A modified barium swallow study (a procedure in which the process of swallowing and the movement of food from the mouth through the esophagus is viewed in order to determine how well the airway is protected during swallowing) is likely to be part of the initial evaluation. The SLP and OT can work together to develop a treatment program, taking all of the assessment information into account. Ongoing discussion with the complete team is warranted in order to measure progress.

FROM THE MANAGEMENT MANUAL FOR PARENTS:

CHARGE syndrome affects the cranial nerves, especially those involved with oral-motor skills and swallowing. Many children remain primarily g-tube fed for years. Those who eat orally often continue to have difficulty with certain textures or consistencies of food. Choking may remain a potential hazard forever. Secondary factors leading to oral-motor/feeding issues include gastroesophageal reflux (GER), cardiac and respiratory complications.

Reflux can lead to aspiration pneumonia and increase the frequency of ear and sinus infections. Pain associated with infections can be the underlying cause of abrupt changes in behavior in children with CHARGE. When sudden changes in behavior (including apparently aggressive or self-injurious behaviors) are seen, medical causes of pain should be ruled out before instituting behavior modification programs.