

ASPIRATION AND DYSPHAGIA IN CHILDREN WITH DOWN SYNDROME

ALGORITHM 1. PCP Management of Feeding/Swallowing Problems

Feeding problems include:

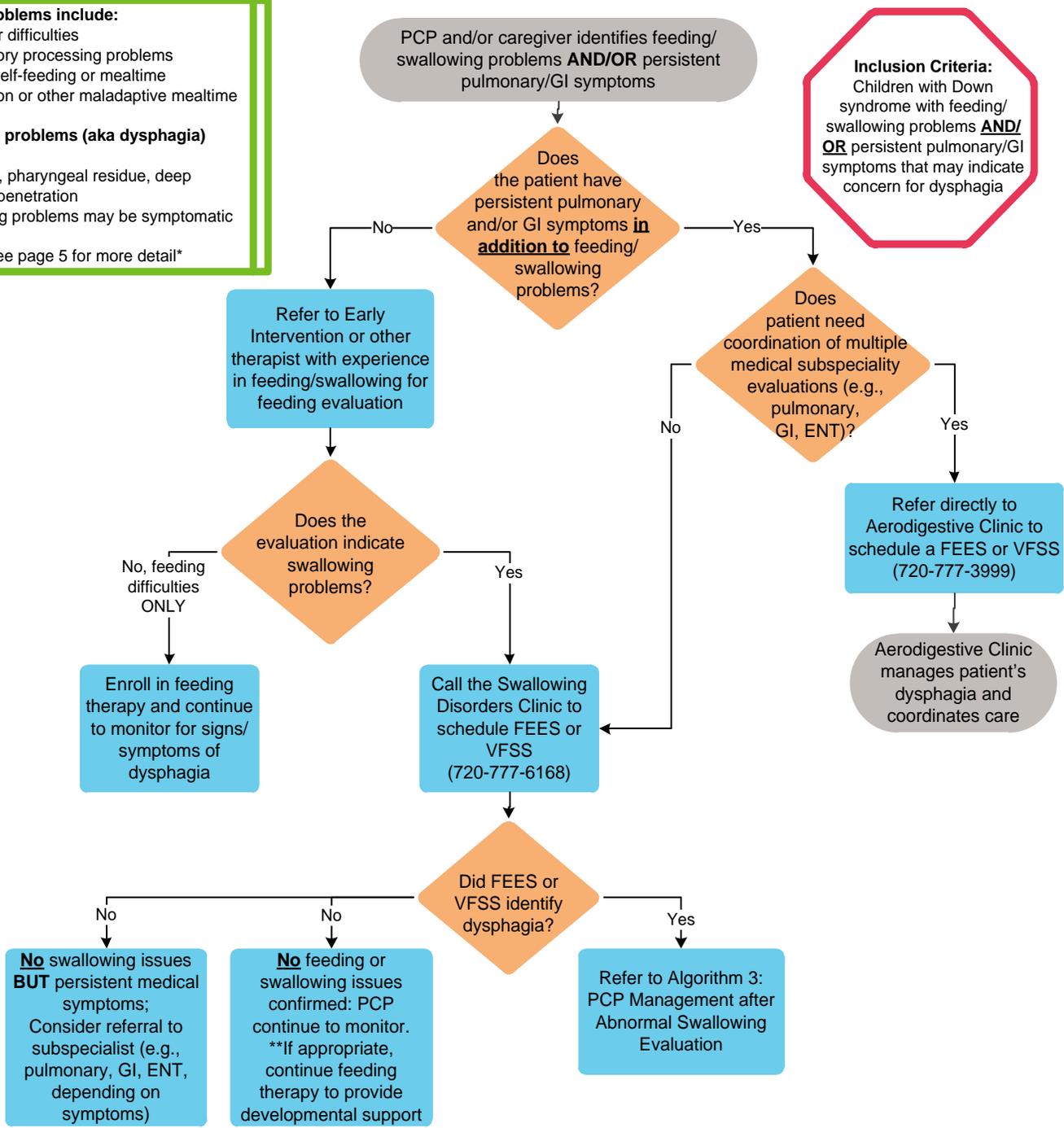
- Oral/motor difficulties
- Oral sensory processing problems
- Difficulty self-feeding or mealtime participation or other maladaptive mealtime behaviors

Swallowing problems (aka dysphagia) include:

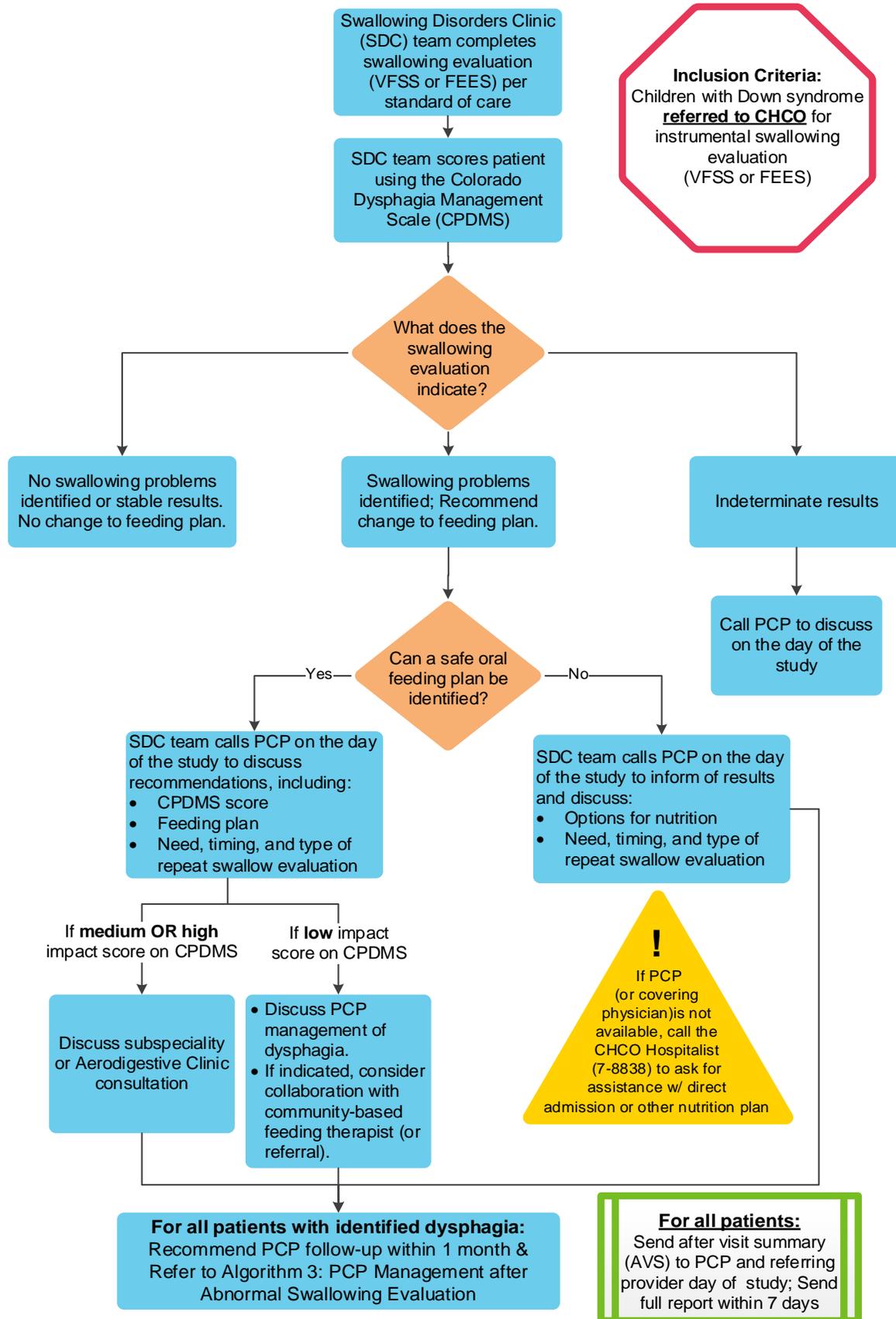
- Aspiration, pharyngeal residue, deep laryngeal penetration
- Swallowing problems may be symptomatic or silent

See page 5 for more detail

Inclusion Criteria:
Children with Down syndrome with feeding/swallowing problems **AND/OR** persistent pulmonary/GI symptoms that may indicate concern for dysphagia



ALGORITHM 2. Swallowing Disorders Clinic Dysphagia Management



ALGORITHM 3. PCP Management After Abnormal Swallowing Evaluation

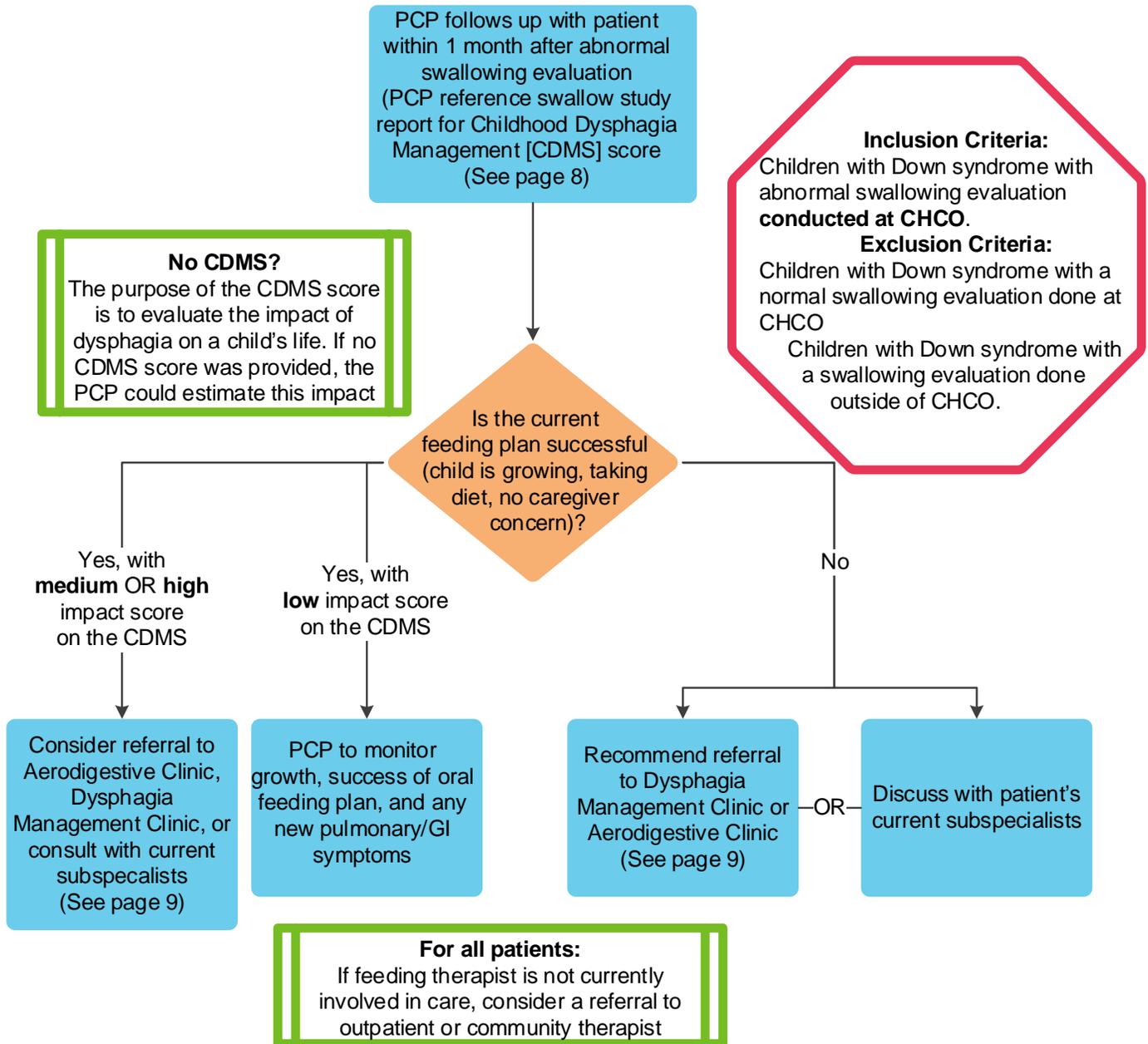


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TARGET POPULATION

Inclusion Criteria

Children with Down syndrome

Exclusion Criteria

Children with acute respiratory illness

KEY POINTS

- Children with Down syndrome have a high risk of morbidity and mortality from pulmonary disease. Aspiration is common in children with Down syndrome, and may contribute to pulmonary morbidity; therefore, primary care physicians should screen all children with Down syndrome for swallowing problems (aka, dysphagia).
- In children with Down syndrome who aspirate, silent aspiration (no clinical symptoms) is common.
- Children with Down syndrome with feeding and swallowing problems or with chronic respiratory and gastrointestinal symptoms should have an instrumental swallowing evaluation (FEES or VFSS).
- Dysphagia management in Down syndrome should be individualized with consideration of severity and persistence of swallowing problems and other factors such as medical comorbidities and family preferences.
- Goals of these guidelines include: supporting providers (PCPs, therapists, etc.) in screening for feeding and swallowing disorders and improving feeding outcomes in children with Down syndrome, decreasing radiation exposure from radiographic swallowing studies by critically evaluating their need and frequency, and improve communication and care coordination among providers treating children with dysphagia.

BACKGROUND | DEFINITIONS

Background

Children with Down syndrome have a high risk of morbidity and mortality from pulmonary diseases such as pneumonia, chronic lung disease, and pulmonary hypertension (Yang *Lancet* 2002). The cause of these pulmonary diseases is multifactorial and can include upper airway obstruction, cardiac defects, lung anomalies, esophageal and gastrointestinal (GI) disease, and immune defects. Children with Down syndrome also have a high-risk of swallowing problems (aka dysphagia), including aspiration, which can further contribute to chronic pulmonary symptoms, morbidity, and mortality. Factors contributing to the risk for swallowing problems in this population include hypotonia, oral motor and oral sensory dysfunction, and airway and GI anomalies such as laryngeal cleft and esophageal stenosis. These considerable risk factors, the high incidence of silent aspiration (no overt symptoms) in this population, and the severity of complications from lung disease, support the need to screen feeding and swallowing problems with history and physical exam in all children with Down syndrome.

Feeding vs. Swallowing problems

It is important to distinguish between feeding and swallowing problems. ***Feeding problems*** can include oral motor difficulties (e.g. difficulty latching to the nipple, difficulty chewing), oral sensory processing problems (e.g. oral aversion, gagging, overstuffing the mouth), difficulty with self-feeding or mealtime participation and other maladaptive mealtime behaviors. ***Swallowing problems*** can occur in the oral, pharyngeal or esophageal phase of swallowing. Swallowing problems are characterized by the underlying physiologic dysfunction and the resultant impact on the bolus of food or liquid (e.g., incomplete glottic and supraglottic closure during the swallowing leading to aspiration; weakness of the pharyngeal muscles leading to residual food or liquid present after the swallow).

Types of Dysphagia (Swallowing problems)

In children with Down syndrome, the most common swallowing problems are deep laryngeal penetration and aspiration (Jackson et al., 2016). ***Aspiration is defined as liquid, food, or secretions passing below the level of the vocal folds into the airway.*** Deep laryngeal penetration is defined as food, liquid or secretions entering the laryngeal vestibule and extending to the vocal folds without being aspirated. Deep laryngeal penetration is a known risk factor for eventual aspiration (Friedman and Frazier 2000). Other swallowing problems such as oral phase difficulties (e.g. inefficient oral transit, oral residue) and pharyngeal residue after the swallow can also occur in children with Down syndrome. Esophageal swallowing difficulties may include food or liquid moving slowly through the esophagus or getting stuck in the pharynx due to impaired opening of the upper esophageal sphincter. Esophageal dysphagia is less common in children with Down syndrome and when present should prompt evaluation by a gastrointestinal subspecialist for anatomic esophageal and GI disease. Children with Down syndrome presenting with any type of swallowing dysfunction should be treated and monitored closely, especially in the areas of pulmonary health and growth.

Evaluating Dysphagia: Instrumental Evaluations (VFSS and FEES)

An instrumental evaluation of swallowing is necessary to accurately diagnose and characterize dysphagia. Due to the high incidence of silent aspiration (no cough or clinical symptoms) in this population, there should be a low threshold for obtaining an instrumental evaluation. Currently available instrumental evaluations of swallowing include the ***Videofluoroscopic Swallow Study (VFSS)*** and the ***Fiberoptic Endoscopic Evaluation of Swallowing (FEES)***. VFSS and FEES are both functional, real time evaluations and are defined as “instrumental evaluations” because the medical team receives direct visual feedback of swallowing. This contrasts with a clinical feeding or swallow evaluation, also referred to as a “bedside” swallowing evaluation, where a feeding specialist can observe feeding skills but cannot directly visualize the child’s swallowing. The goals of instrumental evaluations are to characterize the child’s dysphagia and identify the most appropriate diet and feeding modalities for the patient based on their swallowing physiology. In many cases of pediatric dysphagia, the child’s PCP is involved in recommending a feeding plan. This is because the evaluation of the risks and benefits of ongoing oral feeding with known potential for aspiration requires in-depth knowledge of the child’s medical status and falls beyond the scope of pediatric feeding therapists alone.

Types of Feeding and Swallowing Evaluations

Clinical Feeding Evaluation

A clinical feeding evaluation involves the observation of oral feeding by a speech-language pathologist and/or occupational therapist that specializes in feeding disorders. Additionally, a developmental pediatrician, dietician and/or psychologist may be involved with the evaluation. During a clinical feeding evaluation, the child's oral motor skills, oral structure and function, oral sensory processing, positioning, development, growth, nutrition, social/emotional status, and overall health are considered within the context of the child's feeding difficulties to identify potential contributing factors. Examples of feeding difficulties that would warrant a clinical feeding evaluation include, but are not limited to: inefficient bottle or breast feeding, difficulty advancing food textures as expected for age and development, overstuffing, gagging, oral aversion, challenging mealtime behaviors, and limited repertoire of accepted foods.

Instrumental Evaluations of Swallowing

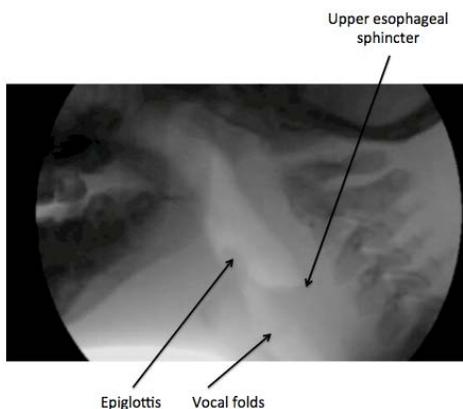
An instrumental evaluation of swallowing involves visualization of the swallow structures and their function during and after active swallowing. Examples of swallowing problems that would warrant an instrumental evaluation of swallowing include, but are not limited to: coughing/choking or red/watery eyes with feedings, wet vocal quality during/after feedings, and poor coordination of breathing and swallowing. In children with Down syndrome, chronic respiratory or GI symptoms or challenges with growth and nutrition may also warrant an instrumental evaluation.

FEES and VFSS studies have two primary goals. The first goal is to evaluate the child's anatomy and baseline swallowing function, including the timeliness of initiation of the swallowing reflex, ability to protect the airway (achieve adequate laryngeal closure and elevation) and ability to completely clear the mouth and pharynx of swallowed food and liquid. The second goal is to determine and recommend a functional feeding plan for the child based on the findings of the exam. A feeding plan may include recommendations for consistency of food/liquid, patient positioning during feeding and appropriate feeding modalities (cups, nipples, utensils, etc.).

Videofluoroscopic Swallow Study (VFSS)

A videofluoroscopic swallow study is conducted in radiology under fluoroscopy. The child is positioned upright, semi-reclined, or in side-lying and is offered various liquid and food consistencies mixed with barium contrast. Swallowing is evaluated as the child consumes the barium meal and as adaptations are made to optimize their airway protection during swallowing (e.g. pacing, positioning). Children across the age span are appropriate candidates for the VFSS and it is typically the preferred exam for initial swallowing evaluations as a view of the oral, pharyngeal, and upper esophageal phases of the swallow can be obtained. Typically, a child should be able to consume an ounce of food or liquid by mouth before being referred for a VFSS.

Image 1. VFSS view of swallowing structures

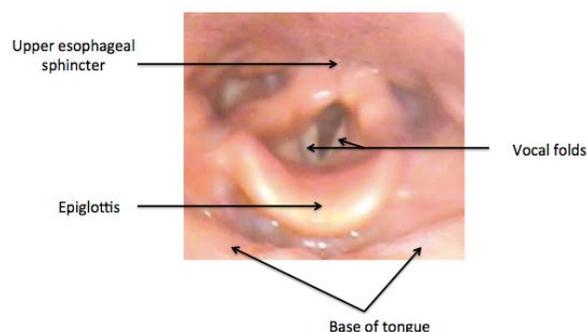


Fiberoptic Endoscopic Evaluation of Swallowing (FEES)

A fiberoptic endoscopic evaluation of swallowing is conducted in the otolaryngologist's office or at bedside for some inpatients. A pediatric-sized endoscope is passed through the patient's nasal passages to the level of the pharynx, and the structures of the larynx and pharynx are viewed from above at rest and during swallowing. In the FEES, blue

or green food coloring is typically used as the contrast agent to enhance visualization of swallowing. Because the endoscopic view using FEES is “top down” and is not a radiographic image, it is also possible during FEES to evaluate the symmetry, structural integrity, and mobility of the structures of the hypopharynx and the patient’s ability to swallow secretions. The image quality of FEES makes it possible to evaluate smaller volumes of food and liquid than is possible during VFSS and a patient does not need to be able to consume a specific amount of food or liquid prior to participating in FEES. As with the VFSS, adaptations are trialed during the FEES to optimize airway protection during swallowing. A FEES is most often appropriate for children age 12 months and younger and children who are age 4 and older developmentally. Children in the toddler age range may have difficulty understanding and cooperating with the exam, but FEES can be considered in this age range with behavioral supports.

Image 2. FEES view of swallowing structures



PCP RESPONSIBILITIES FOR FEEDING/SWALLOWING

Feeding/Swallowing Screening

- We recommend physicians inquire about feeding and swallowing at routine visits in children with Down syndrome of all ages. If there are feeding concerns in children less than 6 months of age who are medically stable, we recommend a clinical feeding evaluation prior to considering an instrumental assessment of swallowing. Recommended feeding/swallowing screening questions:
 - Does child have trouble with feeding, slow feeding, or a decline in feeding?
 - Does your child cough, choke or have red/watering eyes while eating and drinking?
 - Does your child have feeding therapy services in place? How is therapy going?
- Because swallowing problems can be silent (no obvious signs or symptoms), screening of feeding and swallowing concerns includes more than asking about clinical signs and symptoms of dysphagia. Consider the child’s pulmonary status (frequent URI, persistent oxygen requirement), growth and nutrition status and potential medical comorbidities that could impact feeding or swallowing (laryngomalacia, vocal fold paralysis, severe hypotonia etc.). (Bull 2011).
- If no feeding or swallowing concerns are present, continue to monitor feeding and swallowing status at regular well-child checks for children with Down syndrome as feeding/swallowing problems can occur over time as the child is presented with advanced textures and faster flowing systems for drinking.

Feeding/Swallowing Referrals

- **Feeding evaluation:** If the parent reports feeding problems such as inefficient bottle or breast feeding, difficulty advancing food textures as expected for age and development, overstuffing, gagging, oral aversion, challenging mealtime behaviors, and limited repertoire of accepted foods, consider a referral for feeding evaluation. While awaiting referral, PCPs can discuss positioning changes or change of nipple caliber and flow based on their comfort with these recommendations.
 - CHCO Feeding Clinic (Pediatric Oral Feeding Clinic and Individual Feeding Evaluations)

- Phone: 720-777-6168, Fax: 720-777-7299
 - Early Intervention Colorado: 1-888-777-4041
 - **Instrumental swallowing evaluation:** If the parent reports coughing/choking or red/watery eyes with feedings, wet vocal quality during/after feedings, and poor coordination of breathing and swallowing or if the child has pulmonary health problems concerning for aspiration, consider a referral for an instrumental evaluation of swallowing (VFSS or FEES). Note that swallowing problems do not always present with overt clinical symptoms (can be silent).
 - CHCO Swallowing Disorders Clinic (VFSS or FEES):
 - Phone: 720-777-6168, Fax: 720-777-7299
- ** An internal triage process is in place at CHCO to help determine if a child needs a VFSS or a FEES.
- In general dysphagia is a long-term condition rather than an urgent medical problem. If urgent consultation is needed to maintain nutrition and hydration, we recommend calling CHCO One Call at 720-777-3999 to discuss with the hospitalist team on call regarding admission or to discuss with pulmonologist or gastroenterologist on call as needed.

Feeding/Swallowing Management after Evaluation

Actions following a feeding evaluation from CHCO

Once a feeding evaluation is completed, the evaluating therapist will send the report to the PCP. Please refer to feeding therapy if recommended in the community or with a private or hospital based therapist (speech-language pathologist or occupational therapist) with feeding expertise. Continue to monitor progress with feeding and growth/weight gain at regular well child checks.

Actions following an instrumental swallowing evaluation from CHCO

1. Receive results from evaluating team

If study is done at CHCO, PCP will receive a preliminary report the day of the study including CDMS score (see below). PCP will be contacted by phone on the day of the study if a diet change is recommended to discuss the results of the study and plan for ongoing management. PCP to discuss final recommendations with parents after communicating with swallow team.

Childhood Dysphagia Management Scale (CDMS)

If completed at CHCO, the swallow study will be scored using the Childhood Dysphagia Management Scale (CDMS). [See Appendix A](#) for more specifics regarding the CDMS. This score estimates the impact of dysphagia on a child's life. The CDMS may be helpful in determining whether subspecialty follow up is indicated to further evaluate and manage the child's dysphagia.

Low Impact CDMS Score (0-2)

Children with oropharyngeal dysphagia AND low impact CDMS scores, minimal diet changes related to dysphagia, and no significant caregiver concerns should be monitored by their primary care physician to ensure that they continue to have successful feeding plans. Coordination with the child's treating feeding therapist and/or the therapist who evaluated the child in Swallowing Disorders Clinic may be necessary to determine optimal timing of repeat swallow study.

Medium Impact CDMS Score (3-5)

Children with oropharyngeal dysphagia AND medium impact CDMS scores, diet changes that require clinical management, and ongoing caregiver concern, may benefit from coordinated care in the Dysphagia Management Clinic, a multidisciplinary clinic consisting of a pulmonologist, speech-language pathologist or occupational therapist specializing in swallowing disorders, and a clinical dietician. Patients who have alternative feeding plans due to dysphagia are evaluated for pulmonary status, growth, nutrition, and success of recommended feeding modalities and diet.

High Impact CDMS Score AND/OR significant breathing/GI symptoms and co-morbidities (6 and up)

Children with high impact CDMS scores AND/OR significant breathing/GI symptoms and co-morbidities may need evaluation by multiple medical and surgical subspecialties to help evaluate and manage their care. In general, an aerodigestive program is recommended to coordinate and consolidate care. In certain circumstances, subspecialty care outside of an aerodigestive program may benefit individual patients.

2. Monitor Response to Diet Changes/Recommendations

It is recommended that the PCP follow up within 1 month of the swallow study for children who have abnormal results ([see Algorithm 3](#)). Monitor for tolerance of liquid consistency changes, parent follow through with recommendations, access to recommended feeding modalities (cups, bottles) and thickeners, nutrition status, growth, and stooling.

3. Determine timing of next study

The timing and modality (VFSS or FEES) of repeat swallow studies is individualized and should be determined with input from the full medical team, including PCP, subspecialty clinics managing dysphagia and treating therapists. Considerations for repeat swallow studies should include, but are not limited to: change in clinical signs/symptoms of dysphagia, radiation exposure, family goals and child's developmental readiness to progress diet, child's growth and medical status on recommended diet. If ongoing pulmonary concerns suspicious for aspiration are present in children with previously normal swallow studies, consider a repeat evaluation. Consider FEES as an interval study in patients who need multiple repeat swallow evaluations to minimize radiation exposure.

Preparation for repeat swallow studies: For some patients, it is important that they have exposure to feeding modalities and food/liquid consistencies that were not tested in a previous swallow study or were shown to be unsafe in a previous swallow study. An example of this is a child who is bottle fed to provide a slow flow rate but is developmentally ready to progress to a cup. In these cases, the child may benefit from a program of controlled practice with an identified cup and/or consistency under the guidance of a therapist with expertise in swallowing and with close monitoring of pulmonary health from a physician (PCP or managing subspecialists).

CLINICAL MANAGEMENT OF DYSPHAGIA

Subspecialty Clinics for the Management of Dysphagia at Children's Hospital Colorado

In many children with Down syndrome and dysphagia, we recommend multidisciplinary medical evaluation focused on determining the cause of dysphagia as well as assessing lung health, growth, and any associated GI symptoms. The Aerodigestive Program and Dysphagia Management clinic are multidisciplinary clinics at CHCO designed for children with dysphagia. Medical evaluation can also occur with the child's established subspecialists, with communication with the child's existing therapy team.

Dysphagia Management Clinic

Dysphagia management clinic is a multidisciplinary clinic for the medical management of children who have been identified with oropharyngeal dysphagia and would benefit from coordinated care with a team consisting of a pulmonologist, feeding therapist specializing in swallowing disorders, and a clinical dietitian. Patients who have alternative feeding plans due to dysphagia are evaluated for pulmonary status, growth, nutrition, and success of recommended feeding modalities and diet.

Consider referring patients who have ongoing signs/symptoms of dysphagia with recommended diet, difficulty with adequate intake, growth/weight gain with recommended diet, or concerns with thickening (poor tolerance of thickening agent, unable to extract thickened liquids from recommended system).

Aerodigestive Program

The Aerodigestive Program is a multidisciplinary clinic for the comprehensive management of children with complex airway, respiratory, and gastrointestinal digestive tract disorders. The Aerodigestive Program consists of several subspecialties including pulmonary, gastroenterology, otolaryngology, occupational therapists and speech-language

pathologists, and clinical dieticians that specialize in feeding, swallowing and voice, nutrition, social work, and anesthesiology. Special attention is given in the Aerodigestive Program to consolidating required surgical procedures under one anesthesia in a pediatric operating room setting.

Consider referring children with severe growth abnormalities and/or upper airway or GI concerns so that the contribution of GI and airway diagnoses can be evaluated. Also, consider referring children who have persistent dysphagia and need further workup as to cause

1. **Cause of dysphagia** (ENT, Neurology) – in Down syndrome, dysphagia can be anatomic or functional or both. Children should be evaluated by a pediatric ENT surgeon with expertise in swallowing or Down syndrome to evaluate for vocal fold mobility and anatomic airway problems that would be surgically repairable (laryngeal cleft, tracheoesophageal fistula, etc.). In general, an aerodigestive program is recommended to evaluate the airway so that co-morbidities including esophagitis, airway obstruction, and tracheomalacia can be evaluated at the same time; however, patient-specific concerns such as severe obstructive sleep apnea or known palatal problems may warrant evaluation by surgeons with specialties in those fields. Neurologic outpatient evaluation is recommended for children with focal deficits in their neurologic exam or with severe obstructive sleep apnea that could indicate Chiari malformation.
2. **Lung health** (Pulmonology) – Children who have dysphagia are at risk for aspiration pneumonitis and pneumonia associated with chronic cough and wheeze and long-term consequences of repeated structural lung injury and bronchiectasis. The timing of these consequences and the individual factors that may affect a patient's likelihood to get these consequences remains unclear. Children with Down syndrome who have dysphagia should be seen by a pulmonologist to evaluate and monitor their overall lung health. Testing should include chest radiograph, pulse oximetry, and spirometry when possible. Chest Computed tomography scans are the gold standard to evaluate for bronchiectasis, but this imaging is not needed in all children with dysphagia. Flexible bronchoscopy with bronchoalveolar lavage may be useful to evaluation for airway inflammation and infection. Ongoing decisions regarding dysphagia management should include consideration of current lung health.
3. **Growth** (Gastroenterologist, clinical dietician, multidisciplinary team) – Children who have dysphagia are at risk for poor growth due to poor intake, diet changes recommended for safe oral feeding plan and other associated diagnoses. Children should be evaluated by a dietician and/or GI subspecialist if growth is below that expected. This evaluation may include evaluations for celiac disease, endocrine abnormalities, inadequate intake, or malabsorption. Growth should be monitored in children on specialized diets related to their dysphagia (i.e. thickened liquids) to ensure it is maintained.
4. **Vomiting or esophageal dysphagia** (Gastroenterologist, multidisciplinary team) – Children who vomit or have esophageal dysphagia should be evaluated by a gastroenterologist. **Upper gastrointestinal (UGI) fluoroscopy series is recommended in this population and sometimes an esophagram is also useful.** Other available evaluations include esophagogastroduodenoscopy (EGD) and esophageal manometry.

Diagnostic Procedures in Children with Down Syndrome and Dysphagia

The following diagnostic procedures may be indicated in the evaluation of children with Down syndrome with High Impact CDMS Score AND/OR breathing/GI symptoms and co-morbidities. In general, subspecialty medical and surgical evaluation (as documented above) is indicated.

- **Microlaryngoscopy/Bronchoscopy (MLB):** An endoscopic procedure under general anesthesia that evaluates the voice box and airway. A careful evaluation of the larynx (voice box) is performed to check if there is a laryngeal cleft. A laryngeal cleft is an anatomic defect that varies from mild where there is a gap between the interarytenoid muscles (Type 1) but not into the cricoid cartilage to severe where there is an opening from the trachea into the esophagus (Type 3 or 4). If the swallowing evaluation demonstrates significant aspiration, this procedure is recommended to evaluate the larynx for an anatomic anomaly (laryngeal cleft) that may be responsible for the aspiration. This procedure is often performed as part of aerodigestive “triple scopes.”
- **Pulmonary flexible bronchoscopy with or without bronchoalveolar lavage (BAL):** An endoscopic procedure under general anesthesia that evaluates the upper and lower airway. In children with Down syndrome, airway branching can be abnormal and can contribute to breathing symptoms and dysphagia. BAL is a sterile water washing of one section of the lung that is obtained during flexible bronchoscopy to evaluate for inflammation and infection in the lung and airway. BAL can be helpful as children are at

increased risk for airway infection and inflammation. The procedure is often performed as part of aerodigestive “triple scopes.”

- **Upper GI Fluoroscopy series:** An imaging study in which the radiologist administers barium orally or via an NG tube to coat the inside of the esophagus, stomach, and intestine. This would evaluate for possible esophageal causes of dysphagia or cough including vascular rings or tracheal esophageal fistula (TEF). To evaluate for TEF, a specific protocol needs to be ordered prompting the radiologist to look closely for this abnormality.
- **Esophagogastroduodenoscopy (EGD):** An endoscopic study under general anesthesia that evaluates the upper GI tract for mucosal anomalies that could contribute to dysphagia including esophagitis or eosinophilic esophagitis. This procedure is often performed as part of aerodigestive “triple scopes.”
- **Esophageal Manometry:** A study in which a small catheter is placed through a patient’s nose and into the esophagus. The probe on the catheter measures the functional nature of esophageal swallowing. Although rare, this study is the gold standard to diagnose motility disorders of the esophagus.

THERAPEUTICS

The goal of managing dysphagia in children with Down syndrome is to maintain lung health AND to offer sufficient feeding opportunities for development. Adapted oral feeding experiences in the presence of dysphagia allow the child to maintain and develop oral motor skills and interest in participating in meaningful mealtime experiences. To meet these goals, successful feeding plans must be individualized for every patient and their family. In some situations, safe oral feeding plans can be easily adopted (changing type of cup, thickening liquids, etc.); however, for some patients, implementation of these changes is more challenging. Sometimes, no safe oral feeding plan can be identified due to the severity of dysphagia or patient’s inability to consume sufficient oral nutrition with swallowing adaptations. In these situations, we recommend collaboration between the PCP, therapists, and subspecialists. Methods of tube feeding, as well as the potential benefits, challenges and impact on oral feeding development, must be discussed with the family.

Feeding Therapy and Swallowing Therapy

- Feeding and swallowing therapy programs should always be highly individualized to address the child’s specific developmental and sensory processing needs and when applicable the physiological deficits contributing to their feeding/swallowing problems. Regular feeding therapy visits with a speech-language pathologist or occupational therapist with specialized training in feeding and swallowing disorders can help to establish specific goals and therapy strategies to optimize the child’s feeding within the context of their development and medical status. Therapy services may be accessed through early intervention, private therapy clinics, hospital based therapy clinics and multidisciplinary clinics and within the school setting. Communication between the feeding therapist who is regularly monitoring the child’s feeding and swallowing and the medical team is essential.
- Feeding therapy services may target multiple aspects of a child and family’s feeding routine, including but not limited to: optimized positioning, self-feeding, oral motor skills, mealtime behavior and routines, family education regarding appropriate food textures for child’s development, weaning from supplemental tube feeding, introduction of new cups/feeding systems, adaptation of utensils/feeding systems, mealtime communication, and child/family education regarding mealtime pacing.
- Because children are developing cognitive skills and self-monitoring, therapeutic interventions for oropharyngeal swallowing problems are frequently targeted at adapting the pace (e.g. one sip at a time, slower flowing cup system) or consistency (i.e. thickened liquids) of what is presented to the child for safe swallowing function. These adaptive interventions are designed to provide the child with a consistent experience of “safe” (without aspirating) swallowing. In some cases, adaptive positioning and/or swallowing rehabilitation exercises are part of the treatment plan, but these must be used in cases where the patient can understand and effectively implement them.
- [See Appendix D](#) for further resources for feeding/swallowing therapists.
 - CHCO Feeding Clinic (outpatient feeding therapy, intensive feeding therapy and feeding therapy groups):
 - Phone: 720-777-6168, Fax: 720-777-7299
 - Early Intervention Colorado: 1-888-777-4041

Additional Considerations

- **Individualized Education Plan (IEP) and Health Plan:** For children who attend school and have specialized diets, feeding plans, and/or need for supervision for safe oral feeding, the feeding plan should be documented in the “Health Plan” section of their child’s IEP.
- **Oral motor tools/exercises:** Interventions aimed at improving a child’s oral motor skills and/or feeding efficiency should be individualized for each child. There is not a “one size fits all” approach or program because there is wide variability in the developmental areas that influence feeding in children with Down syndrome (e.g. cognitive, behavioral, medical, social, motoric). To date, there are no specific feeding therapy tools/materials or programs that have sufficient research to support global use with children with Down syndrome. The choice to use a specific oral motor tool or exercise should be based on the underlying physiologic problem impacting feeding and on the patient’s specific feeding goals (i.e. use of a pacifier to maintain non-nutritive sucking in a child on nothing by mouth status).
- **Neuromuscular Electrical Stimulation (NMES)** which is sometimes called “Vital Stim” is an intervention for swallowing disorders that has limited research in the pediatric population. Concerns regarding the use of this therapy in children include:
 - No established protocol for placement of electrodes, strength of stimulus, frequency of intervention
 - Children may not have sufficient communication skills to identify whether the stimulus is uncomfortable
 - No research has been done as to potential long term impact of electrical stimulation to muscles of pharynx (throat) in children
- **Swallowing “practice”:** Ideally, children who have undergone instrumental swallowing assessments will have a recommended diet that enables them to protect their airway with the majority of their swallowing experiences. Theoretically, the experience of consistent, “safe” (without aspirating) swallowing will improve both the motor and sensory aspects of swallowing for the patient. Under medical supervision and guidance of a therapist with expertise in dysphagia, patients may benefit from swallowing consistencies/textures and feeding modalities that fall outside of the recommended diet from their last instrumental swallowing evaluation. Trials of diet advancement may be done to prepare a child for a repeat swallow study, to improve oral control with a new food/liquid consistency, and/or for pleasure/quality of life. Because these trials are not being completed during instrumental imaging, it is critical that the risks of this type of intervention are well understood by the family and that the child is under the care of a physician who is closely monitoring pulmonary health.
- **Adaptive Feeding Equipment:** During the swallow study, various feeding modalities (e.g. cup and bottle systems) may be introduced. Decision making regarding therapeutic feeding modalities is based on the child’s oral motor skills, oral sensory processing, oral and pharyngeal swallowing function, and coordination of breathing and swallowing. For children with motor challenges, adapted utensils may also be helpful. Occupational therapists have specialized training in evaluating and recommending adaptive feeding equipment.
- **Positioning:** The child’s positioning during feeding can have a significant impact on their ability to swallow safely. In the Down syndrome population, hypotonia can lead to maladaptive positioning in all age groups and the impact of positioning on swallowing should be evaluated during instrumental evaluations of swallowing. For infants, special consideration needs to be made for providing support at the child’s head, neck and trunk. For some infants, a semi-inclined side-lying position can improve state regulation and swallowing function. This position can be tested during the VFSS by removing the footplate and positioning the table at a slight horizontal incline and during FEES by positioning the infant in sidelying in the caregiver’s arms. Specialized adaptive feeding chairs may be necessary for children who have more significant differences in muscle tone and postural stability.

Thickening

In some cases of oropharyngeal dysphagia, thickening of liquids can improve the child’s ability to control the movement of the liquid in the mouth and protect the airway during swallowing. There are multiple thickening products available on the market that use various agents to thicken liquids (e.g., xanthan gum, rice cereal, cornstarch based). Liquids may be thickened to various consistencies based on findings from the swallow study (i.e. nectar thick, honey thick). When thickeners are introduced, there are potential impacts to the child’s mealtime experience, growth/nutrition, gastrointestinal health and pulmonary health. Close monitoring by the child’s primary care physician, and if needed, by subspecialty providers is recommended (see Algorithms above in Clinical Care Path).

- **Simply Thick:** At Children's Hospital Colorado, Simply Thick (xanthan gum-based) is preferred because it is relatively easy to mix and provides a consistent level of thickening (i.e. does not thicken over time after being mixed). Simply Thick is used off label for children under age 3.
- **PCP and Dietician:** Ensure the child has maintenance of growth and weight gain, improvement in signs/symptoms of dysphagia, acceptance of thickened liquids and access to thickening agents. Additionally, in the infant population, careful diet analysis is needed because use of thickeners can displace calories and nutrients.
- **Feeding therapy:** Feeding therapy follow up may be needed to assist with ensuring the child is able to efficiently consume and accept the thickened liquid.
- **Alternative thickeners and the International Dysphagia Diet Standardization Initiative (IDDSI):** Use of alternative thickeners or recipes should be evaluated by the swallow team with IDDSI Syringe Flow Testing to ensure that the viscosity of the patient's diet matches the safest viscosity swallowed during the instrumental evaluation (<http://iddsi.org>).

Supplemental Tube Feedings

- Supplemental tube feedings are recommended when children cannot safely or efficiently take enough hydration or nutrition orally due to oropharyngeal dysphagia, feeding difficulties or medical comorbidities. Because most families have the long-term goal of oral feedings, it is recommended that children receiving supplemental tube feedings maintain oral stimulation, oral feeding practice and oral hygiene. Oral sensory stimulation activities involve offering pleasurable sensory input around the face and mouth such as interaction with textured teething toys, empty cups and utensils, and enjoyable touch around the face.
- In many cases, children receiving supplemental tube feedings can continue to take some of their nutrition by mouth. For children with severe dysphagia, this may be a very small volume given for pleasure and oral motor skills development. For other children, a more substantial volume of food/liquid textures that they are able to swallow safely may be offered. Recommendations for volume and consistencies offered by mouth should be made by the medical team, including the evaluating swallowing therapists and the physician/s managing the child's dysphagia.
- When a child is ready to be weaned from tube feeding, more specialized nutrition, therapy and medical follow up may be needed. Consider referral to the Pediatric Oral Feeding Clinic: 720-777-6827.

Proton Pump Inhibitor/H2 Blockade:

- Usage of antacid medications is not specifically a treatment for dysphagia. If children are diagnosed with esophagitis during their evaluation of dysphagia, antacid medication can be a useful treatment. Antacid medications are not considered helpful in maintaining lung health with recent articles noting a likely increased risk of pneumonia, but some data questions this correlation¹⁸⁻²⁴. These medications can be considered for treatment of esophagitis associated GERD but should be used cautiously and for limited times under guidance from a gastroenterologist or peri-operatively in the setting of children with aspiration or high risk of aspiration. Due to side effects, these medications should not be used indefinitely without an evaluation by gastroenterology to confirm and guide management.

International Dysphagia Diet Standardisation Initiative (IDDSI)

- Identifies global standardised terminology and definitions to describe texture modified foods and thickened liquids
- Used for individuals with dysphagia of all ages, in all care settings, and all cultures
- Dysphagia diet framework consisting of a continuum of 8 levels (0-7)
- Based on a systematic review of the evidence regarding the impact of drink thickness and food texture on swallowing
- For more information, including written and video tutorials, please go to <https://iddsi.org/>

PARENT | CAREGIVER EDUCATION

The following In Care of Kids handouts are also available on the Epic Education tab:

- Guidelines for Thickening Liquids: Half Nectar Strength – [English](#) and [Spanish](#)
- Guidelines for Thickening Liquids: Honey Strength – [English](#) and [Spanish](#)
- Guidelines for Thickening Liquids: Nectar Strength – [English](#) and [Spanish](#)
- Hidden Thin Liquids – [English](#) and [Spanish](#)
- Videofluoroscopic Swallow Study – [English](#) and [Spanish](#)
- What happens when your child swallows? – [English](#) and [Spanish](#)
- Where to get SimplyThick – [English](#) and [Spanish](#)
- Choking Risks – [English](#) and [Spanish](#)

APPENDIX A. CHILDHOOD DYSPHAGIA MANAGEMENT SCALE (CDMS)

Childhood Dysphagia Management Scale (CDMS)

Directions: The CDMS is to be completed after an instrumental evaluation of swallowing (e.g. VFSS or FEES) to determine appropriate medical home for management of dysphagia. Identify the patient’s swallowing recommendations/restrictions (Section 1) and persistence (Section 2) of dysphagia. When scoring, consider conclusiveness of the swallow study. If you are unable to make diet/swallowing recommendations, do not score using the CDMS. Under Section 2, previous abnormal swallow studies (including at outside facilities) refers to the presence of dysphagia requiring feeding modifications in a past VFSS or FEES (not refusal to comply or oral feeding problems). Document the total score and identify recommended medical home for dysphagia management. Discuss findings with PCP and/or referring provider, who will determine if a referral is made. When evaluating change on subsequent CDMS scores, consider Section 1 only.

Points Assigned	SECTION 1: Swallowing recommendations/restrictions based on VFSS or FEES (Select all that apply)
0	Feeding, diet or texture accommodations (e.g. due to sensory, oral motor, self-feeding, nutritional or other feeding problems) and/or further evaluation of feeding skills or nutrition status is recommended
0	No diet restrictions based on swallow study findings
1	Positioning change (recommend use of sidelying, chin tuck, or other specialized positioning)
1	External pacing for infant suck/swallow/breathe coordination
1	Thicken liquids to IDDSI level 1-slightly thick (½ nectar)
1	System change to slow or limit bolus flow
2	Single sips and swallows (no consecutive swallows)
2	Thicken liquids to IDDSI level 2-mildly thick (nectar)
2	Therapeutic exposure to textures/consistencies that fall outside of recommended diet restrictions for skill development and/or quality of life (i.e. small volumes of thin water in child on thickened diet)
3	Thicken liquids to IDDSI level 3-moderately thick (honey thick)
4	Oral intake/volume restriction for development/pleasure in primarily tube fed child
4	Recommend a complex swallowing maneuver for safety (e.g. Mendelsohn; supraglottic swallow)
4	Dry swallows/empty spoon/liquid wash between nutritive swallows
5	Feeding modifications recommended, but no diet change implemented due to medical team or family decision
5	No liquids by mouth
5	Nothing by mouth; non-nutritive oral stimulation only
Points Assigned	SECTION 2: Persistence of dysphagia (Select all that apply)
0	No dysphagia requiring diet recommendations or restrictions
1	One study requiring diet recommendations/restrictions (includes current study)
2	Two studies requiring diet recommendations/restrictions
3	Three or more studies requiring diet recommendations/restrictions
Total Score (Section 1 + Section 2)	
No score	Unable to score due to inconclusive swallow study

Dysphagia Management Recommendations based on CDMS	
Points on CDMS	Recommended home for dysphagia management
0-2 (low impact)	PCP Management
3-5 (medium impact)	Dysphagia Management Clinic
6 and up (high impact)	Aerodigestive Program

APPENDIX B. CONTACT INFORMATION FOR FEEDING AND SWALLOWING CLINICS AT CHILDREN’S HOSPITAL COLORADO

- Feeding and Swallowing Program (VFSS, FEES, Pediatric Oral Feeding Clinic, Individual Feeding Evaluations, Feeding Therapy): Phone: 720-777-6168, Fax: 720-777-7299
- Dysphagia Management Clinic: 720-777-6750
- Aerodigestive Program: 720-777-6181 [or click here to visit the website](#)
- Clinical Nutrition: 720-777-2691

APPENDIX C. FURTHER DESCRIPTION OF FEES AND VFSS

Table 1. Characteristics and Description of FEES and VFSS

	FEES (Non-radiographic)	VFSS (Radiographic)
View	View is “top down” (camera generally hovers just above the tip of the epiglottis, can be moved)	View is sideways (sagittal) of head and neck, swallow can be seen from mouth to esophagus
Anatomy	A clear image of the structures of the hypopharynx and larynx can be seen	A broader range of structures can be seen, but with less detail
Contrast	Green/blue dye; Powdered barium may also be used due to its coating properties	Barium
Swallow	View disappears briefly during moment of swallow “white out” - can’t detect events during swallow	Comprehensive view of all swallowing phases - oral, pharyngeal, cervical esophageal
Participants	May not be appropriate for children with significant sensory processing or behavior problems. May be challenging with toddler age group, but appropriate for some. May not be feasible in children with choanal atresia or significant upper airway collapse.	Appropriate for all ages. Children with significant sensory processing or behavior problems may require practice to successfully complete this study.

Table 2. Advantages of FEES and VFSS

FEES Advantages	VFSS Advantages
<ul style="list-style-type: none"> • No radiation exposure • Can evaluate a longer meal if patient tolerates • Concomitant upper airway assessment with evaluation of swallowing (concern for vocal fold paralysis or other upper airway anomaly) • Ability to evaluate small volumes and swallowing of secretions • Ability to easily position in parent/caregiver lap, wheelchair or other specialized positioning system, sidelying • Ability to evaluate swallowing during breastfeeding 	<ul style="list-style-type: none"> • View of oral, pharyngeal and upper esophageal phases of the swallow; important baseline/initial assessment of all phases of swallowing • Ability to view depth of laryngeal penetration (predictive of aspiration risk) • Ability to observe nasopharyngeal regurgitation
FEES Disadvantages	VFSS Disadvantages
<ul style="list-style-type: none"> • Comfort/compliance with nasopharyngoscopy • White out during moment of swallow • Inability to view oral and esophageal phases of swallow • Potential compromise of pharyngeal swallow function with use of topical anesthetic (conflicting findings in literature) • May not be feasible if child has choanal atresia or significant upper airway collapse (severe laryngomalacia, retrognathia) 	<ul style="list-style-type: none"> • Radiation exposure • Time constraints due to radiation • Taste of barium • Positioning challenges in radiology suite (e.g. large wheelchairs)

APPENDIX D. RESOURCES FOR FEEDING THERAPISTS

Instrumental evaluation of swallowing needed (all ages):

- Child has pulmonary problems suspicious for aspiration (recurrent pneumonia, unexplained chronic cough or wheeze, recurrent severe respiratory symptoms with viral infections, unexplained hypoxemia)
- Feeding therapy has been provided but child's feeding continues to be inefficient, lengthy and/or uncoordinated and growth continues to be poor
- Child has signs/symptoms of oropharyngeal dysphagia (coughing/choking or red/watery eyes with feedings, wet vocal quality during/after feedings, poor coordination of breathing and swallowing)
- Child has a known upper airway anomaly that could contribute to swallowing dysfunction (e.g. vocal fold paralysis, laryngeal cleft, severe laryngomalacia) or a change in swallowing function following upper airway surgery

Feeding therapy needed:

Infants

- Oral motor difficulties impacting child's ability to latch to breast or bottle
- State regulation issues impacting child's ability to stay alert and organized throughout feeding
- Parent support needed for positioning, feeding schedule, oral motor supports, reading infant cues, or beginning to offer purees (if indicated)
- Feedings are lengthy (more than 30 minutes) and/or inefficient (child taking minimal volumes at each feeding)

Toddlers and older

- Difficulty transitioning to purees or solids from diet of liquids
- Difficulty transitioning off the bottle
- Parent support needed for behavior supports, feeding schedule
- Oral motor and/or oral sensory problems

No intervention needed:

Infants:

- Can feed in less than 30 minutes without breaking off the bottle or breast
- No breathing difficulties associated with feeding
- No excessive loss of liquid
- No coughing, choking, red/watery eyes or wet vocal quality associated with feeding
- Coordinated suck/swallow/breathe sequence
- Maintains alert state throughout feeding without excessive fatigue
- Growth is as expected

Toddlers and older:

- No coughing, choking, red/watery eyes or wet vocal quality associated with eating or drinking
- Child transitions to taking solid foods within a developmentally appropriate trajectory (consider feeding within context of child's overall development)
- Participates in normal mealtime routines at home, school and/or community
- Self-feeding skills are emerging within a developmentally appropriate trajectory
- Oral motor skills are functional for their developmental level
- Growth is as expected

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Pharmacy & Therapeutics Committee – September 7, 2017
 Clinical Pathway and Measures Review Committee – September 12, 2017

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APPROVED BY	 Lalit Bajaj, MD Medical Director, Clinical Effectiveness

REVIEW | REVISION SCHEDULE

Scheduled for full review on September 12, 2021.

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