GLOBAL DOWN SYNDROME FOUNDATION®

Developing an Individualized Feeding Plan for Your Child with Down Syndrome

Global Down Syndrome Foundation Webinar Series

Intro: Michelle Sie Whitten, President & CEO
Presenters: Arwen Jackson, MA, CCC-SLP & Margaret Spring, MS, OTR/L

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Global Down Syndrome Foundation
A Unique Affiliate Model!

The Global Down Syndrome Foundation is part of a network of affiliate organizations that work closely together on a daily basis to deliver on our mission, vision, values, and goals:

Global & Affiliates

- **Global:** was established as a 501(c)3 in 2009 and is "Dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education, and Advocacy"

- **Affiliates are:**
  - Established with a lead gift from Anna & John J. Sie Foundation
  - Must work closely together to benefit people with Down syndrome
  - Must be self-sustaining financially

GLOBAL DOWN SYNDROME FOUNDATION WEBINAR 2018

A Framework for Developing Individualized Feeding Plans in Down Syndrome

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Children's Hospital Colorado
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Overview

1. Feeding Problems in Down Syndrome
2. Swallowing Problems in Down Syndrome
3. Clinical Care Pathway and Colorado Dysphagia Management Scale
4. Global Considerations for Feeding and Swallowing Assessments
5. Resources, Questions and Answers

Feeding Problems

Feeding problems can include:

- Oral motor difficulties (e.g. difficulty latching to the breast, difficulty chewing)
- Oral sensory processing problems (e.g. oral aversion, gagging, overstuffing the mouth)
- Difficulty with self-feeding
- Challenges with mealtime participation and other maladaptive mealtime behaviors

Feeding Research in Down Syndrome

Research is limited with small numbers of participants; measures of feeding are variable and often subjective.

- Jackson et al., 2016: Oral motor and oral sensory difficulties were found frequently (n=116, 84.1%). Descriptive terminology used made analysis of patterns of oral motor and oral sensory dysfunction in the population as a whole more difficult

- Smith et al., 2012: Observation of eating and drinking in a group of 23 adults with Down syndrome with no reported oral feeding difficulties; coughing with feeding was frequently observed. Feeding behaviors were present that were socially unacceptable and felt to impact quality of life

- Lewis & Kritzinger, 2004: "Specific feeding intervention was required for low muscle tone and positioning of the infant and encouragement of breast feeding"

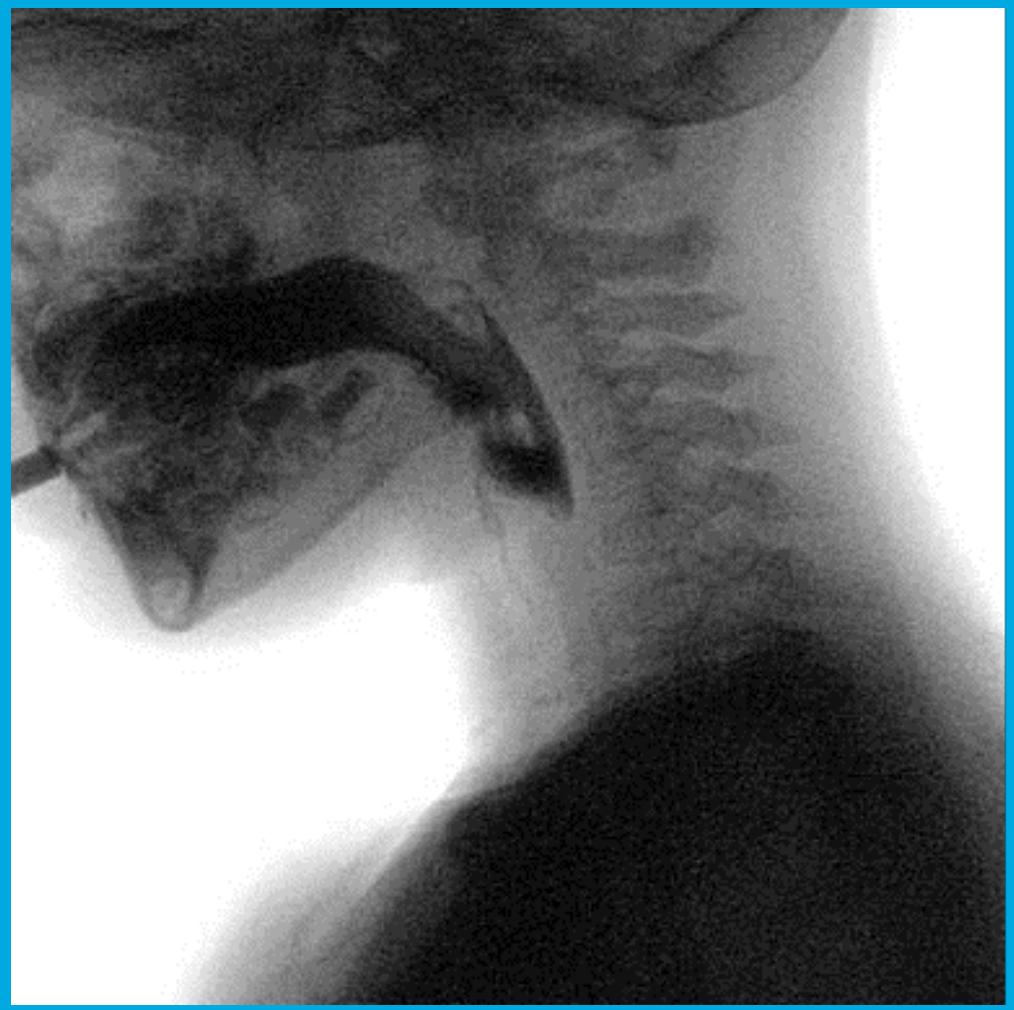
- Spender et al.,1996: "Food refusal and failure to progress through a normal sequence of food textures are often reported, speculatively many reasons may underlie this difficulty including hypotonia, macroglossia, smallness of oral cavity, specific oral motor dysfunction, overall developmental delay, and intercurrent illness"

Swallowing Problems

Oral phase difficulties: Difficulties extracting liquid from a breast, bottle or cup, chewing, or controlling food or liquid in the mouth.

Pharyngeal (throat) phase difficulties: May include delay in starting the swallowing reflex, poor timing of closing off the airway before or during the swallow, and having residual material left in the throat after the swallow. These problems can lead to aspiration, or entry of food or liquid into the airway.

Esophageal difficulties: May include food or liquid moving slowly through the esophagus or getting stuck.



Swallowing Research in Down Syndrome

- Evidence-based practice drives care
- 3 studies have been done to study dysphagia (swallowing disorders) in Down syndrome
  - Of kids referred for a study, about 50% are identified as having swallowing disorders
  - The most common swallowing problems seen are aspiration and deep laryngeal penetration
  - In children with Down syndrome who aspirate, the majority aspirate silently (with no coughing or change in outward appearance)

Frazier & Friedman (1998), Jackson et. al (2016), O'Neill & Richter (2013)

CHCO Clinical Care Path for Dysphagia and Down Syndrome

- Created by a team of doctors, therapists, and family members to help provide feeding plans and medical management plans for children with Down Syndrome and swallowing difficulties
- Outlines a pathway for primary care provider management of feeding/swallowing problems
- Provides resources for primary care providers, other physicians working with the child (such as ENT or pulmonology) and therapists

Colorado Dysphagia Management Scale (CDMS)

- Scale developed to guide evaluations and interventions that should be considered for children with dysphagia
- Score reflects the restrictiveness of the recommendations made during the instrumental swallowing assessment (VFSS or FEES) and is weighted with more restrictive recommendations receiving a higher score
- The number of abnormal swallow studies and worsening findings are also factored into the final score

Global Considerations for Feeding/Swallowing Assessments

1. Development
2. Environment
3. Physiologic
4. Medical

Development: Overview

- **A child's feeding/oral motor skills are often in alignment with skills in other areas of development.**
- Consider:
  - **Cognition and Behavior**
    - *Challenges in concentration, communication, memory, and task performance may impact mealtime performance*
  - **Gross Motor**
    - *Several physical characteristics affect development of gross motor skills. The primary physical factors are: hypotonia, ligamentous laxity, decreased strength, short arms and legs, and medical problems. The influence of each factor is different for each child. (Winders, 2013)*
  - **Fine Motor**
    - *Anticipated delays due to structure of the hand, lower muscle tone, joint laxity and decreased hand strength.*
    - *Do the mealtime tools (seat, utensils, cup/bottle) support or interfere with the mealtime task?*
  - **Non-Nutritive and Nutritive Oral Motor Skills**
    - *A clinical assessment will identify skills as functional, delayed, impaired, disorganized, and/or dysfunctional.*
    - *Differences in structure and function may impact a child's ability to eat more advanced food textures.*
    - *Differences in muscle tone and motor delays impact hand to mouth exploration.*
  - **Communication**
    - *Does the child's communication skills support or interfere with participation in feeding?*

Development: Fine Motor (categorized by month)

Self Feeding Motor Milestones	Typical peer	Peers with DS early (10-33%)	Peers with DS Representative (75-95%)
Hold bottle	6-8	5-8	16-27
Self feed with fingers	8-12	9-10	20-22
Feed with spoon	15-20	28-33	42-72
Drink from straw	20-24	13-27	36-60
Drink from open cup	22-36	28-42	66-90
Feed with fork	36-48	28-57	66-90

Frank and Esbensen, 2015

Development: Therapeutic Strategies

- Meet child at his/her developmental level and progress to the next stage of development.
- Select supportive seating system during mealtime to work towards grasping and oral motor skill development.
- Address working toward postural control *away* from meal time. (*e.g. avoid use of mobile seat cushion during meal*)
- Use positive reinforcements for pleasant and rewarding mealtime experiences.

Development: Takeaways/Resources

- **Are the appropriate developmental therapists involved**?
  - Occupational Therapy: addresses oral motor, oral sensory processing, sensory processing, fine motor/utensil use, seating and positioning, environmental modifications, mealtime routines, vision
  - Physical Therapy: addresses gross motor, seating and positioning, tone, postural control
  - Speech Therapy: addresses oral motor, pharyngeal dysphagia, communication
  - Behavioral therapist: addresses behaviors, reinforcements, maladaptive behaviors, and leaning
  - Educational Specialist: determine if safe feeding plans are in place in the school setting

- **Consider:**
  - Referring to therapies as early as possible. *Consult with child's physician and obtain appropriate referrals.*
  - Focus on improving the quality and efficiency of movement.
  - Teamwork: support collaboration with school, home and private therapists to maximize outcomes.

Environment: Overview

- **The mealtime environment should support the child's ongoing development of feeding skills.**
- Consider:
  - What adaptations can be made for better mealtime participation and safe eating habits (supportive seating, positioning supports)?
  - Are there concerns with sensory processing?
  - How can you alter visual presentation of foods to encourage eating (i.e. offer one food at a time, high contrast between food and plate)?
  - What distractions are present during mealtime?
  - Is the feeder prepared with mealtime materials easily accessible?
  - Is there a consistent mealtime structure and routine?
  - Is a School Health Plan in place?
  - What are the language demands at mealtime?

Environment: Therapeutic strategies

- Is ***adaptive equipment*** necessary to improve independence or reduce demand of task?
- Are ***accommodations*** needed to support the child's ability to integrate concentration, communication, memory, and task performance during meals? (i.e. supervised meals, visual schedules, use of a mirror to clear oral cavity)
- What is the ***family structure and dynamics***?
- How can others adapt to a family's ***cultural feeding practices***?
- Can a social worker or a behavioral therapist help address concerns with ***family's support system***?
- What is the ***"just right" challenge*** to allow time to process new information and allow frequent practice?
- How can adults **offer *modifications at mealtime*** to address sensory hypo-responsiveness and/or hyper-responsiveness?
- What are creative ways to ***support mealtime engagement*** in a variety of contexts and environments (i.e. video modeling)?

Environmental: Takeaways

- Resources to support social environment include social work, behavior specialist, psychologist, mental health supports, PT, OT, SLP= **It's a TEAM!**
- Consider vision supports if needed
- Task analysis across environments can be key to determining why a child is successful in one environment vs another (communication, familiar vs unfamiliar feedings, positioning, sensory processing, distractions, culture, behavior).
- Assess what adaptive equipment is available across settings.

Physiologic: Overview

- Can the child achieve a physiologic state that supports the feeding goals you are trying to achieve?

- Consider:
  - *Breathing*
  - *Alertness/State regulation*
  - *Endurance/Fatigue*
  - *Sensory processing*
  - *Positioning*
  - *Muscle tone*
  - *Difficulties in relation to time (beginning, middle or end of the feeding)*

Physiologic: Therapeutic Strategies

- Positioning for breathing and stability (adequate support at head, neck and trunk, foot bracing, swaddling)
- Check oxygen saturations with feeding
- Pacing for suck/swallow breathe coordination
- If fatigue, concentrated formula or partial oral feeding
- Training parents/caregivers to provide infant driven feedings
- Consider sensory regulating activities before the meal
- Counsel families on appropriate length of mealtimes for attention and endurance

Physiologic: Takeaways

- There's a reason for what you're seeing!
- Think about what is underlying the feeding problems you are noticing.
- How does a feeding change over the course of the meal?
- When is it working and when is it not? Use what's working to adapt.
- Are the appropriate specialists involved to evaluate/support (for example Occupational therapy for sensory, ENT for airway management)?

Medical: Overview

Does the child's medical status support the feeding goals in the treatment plan and ability to participate in feeding therapy?

Medical Area	Status	Supports Feeding	Interferes with Feeding
Pulmonary	*e.g. chronic respiratory infections*		
Cardiac			
Vision/Hearing			
Gastrointestinal	*e.g. gastroesophageal reflux*		
Neurodevelopment			
Upper airway			
Orofacial structures			
Dysphagia			
Growth/Hydration/Nutrition	*e.g. requires a supplemental formula*		
Other			

Medical: Therapeutic Strategies

- Communication between home providers and medical providers is essential; consider communication binder or bring notes from treating therapist to medical appointments
- Feeding plan may need to be fluid based on the medical status. For example: medical team may recommend a strict dysphagia diet in a child with chronic respiratory infections or may loosen restrictions with a child with healthy lungs
- Dysphagia: Aspiration is almost always silent in children with Down syndrome. Changes in feeding plan should be done in consultation with the medical team.

Medical: Takeaways

- Keep the big picture in mind
  - *Support feeding development and progress; work within the confines of comorbidities*
- Don't forget about dysphagia; lungs are for life
- It takes a village: be a part of coordinated care
- Gather information about the child's medical status
- Keep in mind that surgery with associated complications can impact motor development and may cause further delays

Takeaways

- Parents are critical team members
- Don’t forget about the whole care team; collaboration=improved outcomes
- Consider a strengths based model of care
- When developing feeding goals; do so within the context of the whole child
    - *Surgery*
    - *Fine motor*
    - *Dentition*
    - *Growth*
    - *Cultural preference*
- Use the framework to guide task analysis (development, environment, physiologic, medical)

Resources

1. **To access the clinical pathway for Aspiration and Dysphagia in Down Syndrome go to:**

   https://www.childrenscolorado.org/globalassets/healthcare-professionals/clinical-pathways/aspiration-and-dysphagia-in-children-with-down-syndrome.pdf

   OR Google "Clinical Pathways Children's Colorado

2. Screening Tools:
   - Children's Hospital Developmental Screening Tool
   - Significant Aspects of Normal Development During the First Year of Life (Rona Alexander, Reggie Boehem, Barbara Cupps, 1993)
   - Developmental Acquisition of Feeding Skills (Morris S.E.& Klein., M.D., 2000)
   - Fine Motor and Self Care Milestones for Individuals with Down Syndrome (Frank K & Esbensen A.J. 2015)
3. Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals (Winders, 2013)
4. Children's Hospital Colorado Services
   - Multidisciplinary Feeding Evaluations (Sie Center, Aerodigestive Program, and the Pediatric Oral Feeding)
   - Instrumental Evaluations of Swallowing (Videofluorscopic Swallow Studies and Fiberoptic Endoscopic Evaluation of Swallowing)
   - Dysphagia Management Clinic for Children with Down Syndrome
   - Therapy Models of Care: Individual, Co-treatments, Intensives, and Group

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Thank you!

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