

# Fundamental Approaches to Pediatric Feeding Disorders



Tools for critical thinking and problem-solving

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## Financial Disclosures

- Full time employee of Concord Hospital, Concord NH for which I receive a salary
- Receiving and honorarium from The Maine Speech Language and Hearing Association for presenting at this conference.

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## MSHLA Survey and Committee discussion for this presentation...

- Evaluation + criteria for instrumental evaluation
- MBSS –getting the information needed to safely treat.
- Multidisciplinary collaboration
- Intervention strategies
- Family-centered care
- Supporting safe feeding at childcare and school
- Competencies-How to handle if a colleague is not competent to manage a PFD child?

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### Morning Learning Objectives (cont):

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graph TD
    A[1. Describe key incidence and prevalence data and five high risk conditions and symptoms for which PFD are frequently associated and why.] --> B[2. Identify three: readily available PFD screening/assessment tools; medical criteria for instrumental evaluation of the swallow; strategies to insure instrumental evaluation captures the goals of the study.]
    A --> C[3. Complete the training with 3-5 PFD tools/resources to build your competencies to advocate for and serve children with PFD and their families.]
    B --> C
  
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1. Describe key incidence and prevalence data and five high risk conditions and symptoms for which PFD are frequently associated and why.
2. Identify three: readily available PFD screening/assessment tools; medical criteria for instrumental evaluation of the swallow; strategies to insure instrumental evaluation captures the goals of the study.
3. Complete the training with 3-5 PFD tools/resources to build your competencies to advocate for and serve children with PFD and their families.

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### Who are you ? Who do you serve? Why did you come?

Who are you ?

- ▀ FCESS SLP
- ▀ School SLP
- ▀ Private Practice SLP

Who do you serve?

- ▀ 0-3 ?
- ▀ Preschool age ?
- ▀ School age ?
- ▀ All age children ?

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### This presentation is for you and those you serve. We have little time to cover A LOT so PLEASE....

- ▀ Ask your questions
- ▀ Make me clarify
- ▀ Connect with me at another time if you need resources or have questions ?

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PFD stress the family all day everyday

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Pediatric Feeding and Swallowing Disorders: Incidence and Prevalence.

- Conservative evaluations estimate that PFD affects more than 1 in 24 to 37 children under the age of 5 in the United States (ref: Feeding Matters: [https://www.feedingmatters.org/what-is-pfd/?oclid=Ci0KCCQwK5bBhDaARIsACzmALRo4G\\_1ShKUMPlvuEzZyGh2l8lWlfqbAPL\\_mmlhsN2zt99wtvZ1ZwaAhZpEA\\_lw\\_wcb](https://www.feedingmatters.org/what-is-pfd/?oclid=Ci0KCCQwK5bBhDaARIsACzmALRo4G_1ShKUMPlvuEzZyGh2l8lWlfqbAPL_mmlhsN2zt99wtvZ1ZwaAhZpEA_lw_wcb))

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### Incidence and Prevalence

An estimated 116,000 newborn infants are discharged from short-stay hospitals with a diagnosis of feeding problems, according to the *National Hospital Discharge Survey* from the CDC (National Center for Health Statistics, 2010).

**Prevalence is estimated to be 30%-80% for children with developmental disorders** (Arvedson, 2008; Brackett, Arvedson, & Manna, 2006; Lefton-Greif, 2008; Manikam & Perman, 2000).

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## Incidence and Prevalence

- The **odds of having a feeding problem increase by 5 times in children with autism spectrum disorder (ASD)** compared with children who do not have ASD (Sharp et al., 2013).
- Prevalence rates **feeding disorders in children with craniofacial disorders are estimated to be 33%–83%** (Caron et al., 2015; de Vries et al., 2014; Reid, Kilpatrick, & Reilly, 2006).
- \*\*\* Concord Hospital: 50% of our NICU graduates need on-going care

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Thank You For Coming!



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PFD: There is a building evidence base but still many.....



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## What is a Pediatric Feeding Disorder ?

- Impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill and/or psychosocial dysfunction.

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## What is ARFID ? : Avoidance Restrictive Food Intake Disorder



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## What is ARFID ? : Avoidance Restrictive Food Intake Disorder

- New diagnosis added to the DSM 5 Previously referred to as Selective Eating Disorder.
- An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following:
  - Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
  - Significant nutritional deficiency.
  - Dependence on enteral feeding or oral nutritional supplements.
  - Marked interference with psychosocial functioning.

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## What is ARFID ? : Avoidance Restrictive Food Intake Disorder

- The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.
- The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way in which one's body weight or shape is experienced.
- The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention.

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## ARFID and PFD

- "If a patient has a diagnosis of ARFID, it may be worth reassessing from the pediatric feeding disorder (PFD) perspective to see if the cause of feeding difficulties might include a medical or skill dysfunction, and not be purely behavioral."
- -Dr. Richard Noel, Feeding Matters Volunteer Medical Director



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## Case Study Alert



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**PFD evaluation covers 4 Domains**

- **Medical**  
Structure and function of the cardiovascular, digestion, neurological and respiratory systems.
- **Nutritional:**  
Risk of malnutrition, overnutrition, micronutrient deficiency or toxicity, and dehydration that may adversely impact growth, development, and health.
- **Feeding skill:**  
Delays and/or differences with sucking, biting, chewing, sipping and/or swallowing
- **Psychosocial:**  
Psychosocial factors related to the child, caregiver, and feeding environment that adversely affect interpersonal interactions and relationships

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**PFD**

- Mild: generally growing efficiently
- Moderate: not growing sufficiently without nutritional supplementation
- Severe: may require either full or partial nutritional support via tube feeding.

Goday et. Al 2019

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**Studies thus far indicate....**

Feeding problems :

- Result from multiple contributing factors that often occur simultaneously.
- Are complicated by development, growth and changing structures.

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**Solving PFD for each child means....**

By virtue of the definition of PFD:

- Clinical Interdependence versus independence is necessary
- Seeking out help from other professionals is respected and expected
- The learning curve is continuous and steep with many unknowns ahead
- You have the honor of joining families in an intimate aspect of their lives

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**Solving PFD for each child means....**

- Close trusting partnerships with families and, others who serve them, to build a supportive, problem-solving team around each child and family;
- Looking beyond your scope and engaging the range of expertise needed;
- Being thorough with information gathering-from pregnancy and birth history forward (even for an older child!)
- Using history, clinical information, parent information and priorities to establish an initial working hypothesis.
- Using your knowledge, information from other professionals to test, refine and revise that hypothesis.

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**Solving PFD for each child means being committed to:**

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graph TD
    A[Improving all aspects of feeding, including safety, quality of life for the child and family.] --> B[Critical and collaborative thinking.]
    B --> C[Differential diagnosis and dynamic problem-solving.]
    C --> D[Understanding the family's social context and making recommendations that are realistic and doable for them.]
  
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Many parents are concerned about their children's feeding and nutrition. What parent indicators suggest further evaluation ?

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### Infant and Child Feeding Questionnaire (ICFQ)

- Developed by Feeding Matters
- Authored in partnership with internationally renowned leaders representing multiple disciplines related to feeding.
- Age specific tool designed to identify potential feeding concerns and to facilitate discussion with members of a child's healthcare team.
- According to a seminal study published in the 2020 Journal of Pediatrics the ICFQ has been shown to accurately identify and differentiate PFD from picky eating for children 0-4 years of age based upon caregiver responses to 6 questions.

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#### 6-QUESTION SUBSET

Does your baby/child let you know when he is hungry?	YES	NO
Do you think your baby/child eats enough?	YES	NO
How many minutes does it usually take to feed your baby/child?	<5	5-30 >30
Do you have to do anything special to help your baby/child eat?	YES	NO
Does your baby/child let you know when he is full?	YES	NO
Based on the questions above, do you have concerns about your baby/child's feeding?	YES	NO

Red flag answers are in orange. If 2 or more of your answers are orange please contact your pediatrician.

Concerned? Take the full questionnaire:  
[feedingmatters.org/questionnaire](https://feedingmatters.org/questionnaire)

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## Why don't kids eat?

- **Pain:** digestion-GER, esophagitis, colitis, stomach pain; sore mouth and/or throat (thrush, virus) enlarged tonsils.
- **Discomfort**-nausea, distended stomach, NGT/OGT in place
- **Poor hunger drive**-allowed to graze, poor detection of hunger/fullness; energy consumed by respiratory/cardiac needs; on a medication that diminishes hunger drive (some cardiac and ADHD medications; poor interoception.

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## Why don't kids eat?

- **Altered** motor, oral-motor and/or sensory processing skills
- **Paternal differences/ reduced strength& rapid fatigue/challenges with coordination** can impact coordination of sucking, swallowing and breathing for bottle and cup drinking; poor chewing skills impacting safety (choking) and/or efficiency (jaw weakness? Poor tongue mobility? Challenges coordinating tongue and jaw movement?)
- **Sensory hyper and hypo sensitivities** making it difficult for them to tolerate and or discriminate flavors/temperatures/textures in order to engage the appropriate motor plan.

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## Why don't kids eat?

Other child factors: temperament, cognition/cognitive flexibility, attentional challenges; learned avoidance/traumatic experiences.

Parent factors: own beliefs and relationship with food; challenges with establishing meal and snack routines that support hunger drive and satiety; limited understanding of feeding skill development; limited/poor modeling of skills; food insecurity; challenges with setting limits/establishing expectations; use of coercing/tricking/distractions; inconsistent parenting.

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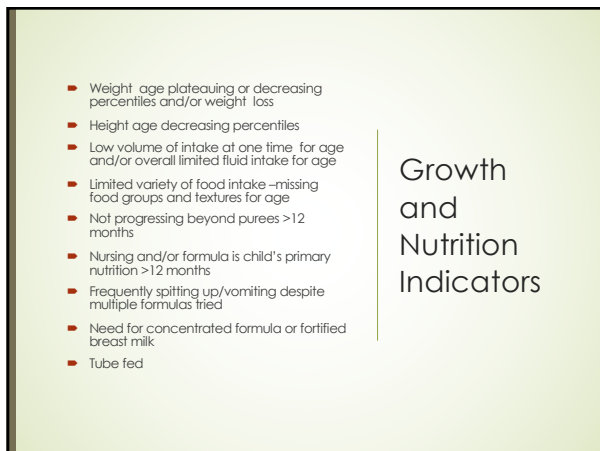
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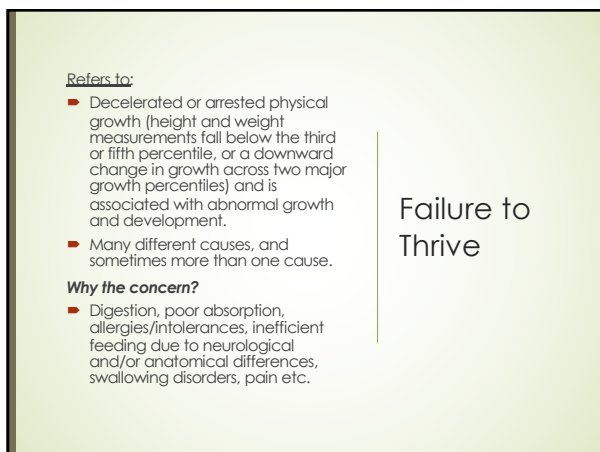
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- Wet voice quality, noisy breathing or congestion with eating and/or drinking
- Throat clearing, coughing, gagging, choking, sneezing with eating and/or drinking
- RR > 60 during feedings
- Dusky spells during or after feeding /apnea spells

### Respiratory Indicators

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### Early Feeding Indicators

- Difficulty with breast or bottle feeding
- Difficulty to arouse for feeding > 4 weeks
- Frequent low volume feedings 2-3 oz. >3 months
- Lengthy feedings (>30 minutes)
- History of prolonged tube feeding
- Excessive leakage from around the nipple
- Feeding problems arising/worsening at > 2 months of age



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### Significant Food Allergies

Refers to:

- milk, eggs, soy,
- peanuts, tree nuts, sesame
- fish and shell fish
- Wheat, corn

**Why the concern?**

Families may need nutrition support. Eliminating foods with allergens can cause children to have nutritional deficiencies requiring supplementation and label reading can be tricky. Food allergies can co-exist with, feeding aversions, extreme food selectivity and other developmental disorders.

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## Oral Motor Function Indicators

Open mouth posture at rest  
Frequent food/liquid loss from lips  
Tongue protrusion at rest and/or with swallowing  
Drooling > 2 years of age

Difficulty with feeding transitions (breast to bottle, etc.)  
Difficulty with advancing textures (purees to table foods. Etc.)  
Lengthy meal times (>30 -40 minutes)

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## Sensory and Cognitive indicators

Highly restricted with taste, texture, color, shape, etc. interfering with nutritional intake  
Drastic drop in food range @ 15-28 mos.  
Reliance upon high feedback foods (zingy/crunchy)  
Can only sit very briefly for meals and snacks  
Unusually short attention for meals

Drowsy/hyper alert/fussy during mealtimes  
Relies upon distractions to eat and/or drink.  
Symptoms of feeding aversion  
Atypical mealtime behaviors  
Does not fuss or report hunger.  
Does not recognize fullness

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We have identified a child likely has PFD, where do we begin ?




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“When the cause of dysphagia is not obvious: Sort through the treasure and surprises in the medical record.” (Coyle, 2014 see ref. 5 )”

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## Family History

- Digestive Disorders
- Allergies/Intolerances
- Substance abuse
- Developmental disorders
- Genetic disorders (muscular dystrophies, cardiac, respiratory, etc.)
- Craniofacial disorders-not (yet) linked to a genetic disorder
- Eating disorder among family members

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## Prenatal and birth history

- Any concerns monitored during pregnancy ? Polyhydramnios ?
- IUGR
- Apgar Scores ?
- Perinatal complications-needed respiratory support (Asphyxia ? HIE protocols?)
- Birth weight?
- Prematurity ?
- In-Utero substance exposure (Alcohol? Opioids? In treatment ? Use of SSRIs)

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## Prenatal and birth history

A closer look

Why the concern?

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## Polyhydramnios

- Definition: excess accumulation of amniotic fluid
- Common causes: gestational diabetes, **fetal anomalies that disturb fetal swallowing of amniotic fluid**, fetal infections.
- In utero there is a dynamic equilibrium between the production and resorption of amniotic fluid. It is reabsorbed **via fetal swallowing** and intramembranous and intravascular absorption.

### Why the concern?

A disturbed equilibrium in amniotic fluid can be the result of compromised swallowing dysfunction in the infant. [ 4 ]

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## Intrauterine Growth Restriction: IUGR

### Refers to:

- poor growth of the fetus in utero
- Means the baby weights <90% of expected wt. for gestational age
- Because of maternal, placental, fetal or genetic cause.

### Why the concern?

Challenging to feed: anatomical differences, poor endurance, low tone/weak, challenges with coordination of suck, swallow and breathing.  
Linked with genetic and developmental disorders

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## APGAR Scores

- Quick test performed on a baby at 1 and 5 minutes after birth.
- Measures five things to check a baby's health: Appearance (color), Pulse, Grimace (reflex irritability), Activity, Respiration



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## APGAR Scores

Apgar Scale (evaluate @ 1 and 5 minutes postpartum)			
Sign	2	1	0
<b>A</b> Activity (muscle tone)	Active	Arms and legs flexed	Absent
<b>P</b> Pulse	>100 bpm	<100 bpm	Absent
<b>G</b> Grimace (reflex irritability)	Sneezes, coughs, pulls away	Grimaces	No response
<b>A</b> Appearance (skin color)	Normal over entire body	Normal except extremities	Cyanotic or pale all over
<b>R</b> Respirations	Good, crying	Slow, irregular	Absent

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## APGAR SCORES

- One minute score (Apgar 1) is considered an indicator of how well the baby did with the birthing process
- Five-minute score (APGAR 5): indicates how well the baby is doing outside the mother's womb and has been correlated with neonatal survival and long-term comorbidities

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## APGAR Scores

### Why the concern?

- Although Apgar scores are not intended for the prediction of neurological morbidities, research findings indicate that Apgar scores may be used, possibly independently or in combination with other measures, as a predictor of later neurological/ developmental morbidities among term infants [38,54]
- Research to date indicates for pre-term infants a low APGAR score was not independently associated with long-term outcome whereas other co-morbidities of prematurity (brain bleeds, cardiac and respiratory conditions) have been. [38]

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### Prematurity: The highest CO- morbidity

- < 28 weeks gestation
- Birth weight < 1000 grams
- Grade IV bleed
- Abnormal MRI
- CLD (chronic lung disease)
- Perinatal asphyxia (HIE/PVL)
- High NAS score

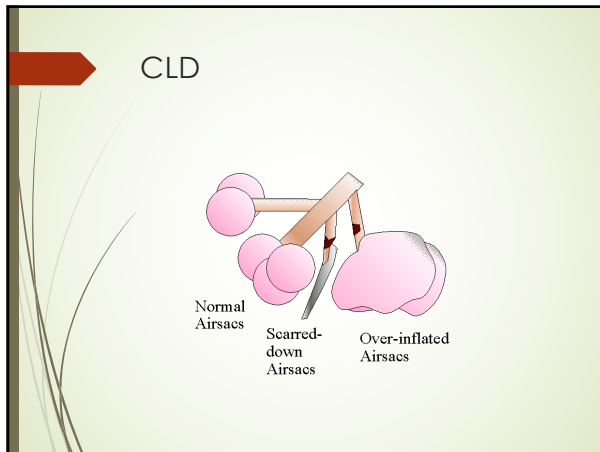
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### Prematurity

#### Why the concern?

- Neurobehavioral instability Vulnerability to becoming rapidly overwhelmed by sights, sounds, touch (overload is baby specific) which shuts down or significantly disorganizes oral feeding (also referred to as neurobehavioral disorganization-very early sensory processing)
- BPD-bronchopulmonary dysplasia-the most common Chronic Lung Disease (CLD) in premature infants, naturally causes a high respiratory rate (RR) naturally challenges coordination of sucking, swallowing and breathing.

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Prematurity (continued)

**Why the concern?**

- Tonal differences impact body wide stability
- Oral reflexes may be diminished/absent.
- Intraventricular Hemorrhage (IVH) and PVL can interrupt neuron migration/white matter formation and interfere with coordination of the swallow
- Lack of developed fatty cheek pads impacts jaw stability and therefore feeding efficiency.
- Disorganized/dysfunctional sucking

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What about LPI ? Late Preterm Infants

■ LPIs (34-36 weeks gestation): An increasing amount of evidence indicates that late preterm infants are more likely to experience feeding issues that may persist through childhood

**Why the concern?**

- lower oromotor tone;
- poor sucking-swallowing-breathing coordination
- disturbed sleep-wake cycles,
- prolonged nasogastric tube feeding and delayed oral feeding independence
- immature gastrointestinal function

All these variables can interfere with the successful initiation and continuation of breastfeeding, resulting in its early cessation. Hence, the breastfeeding rates of late preterm infants are lower than those of full-term infants despite the widely acknowledged health benefits for infants and mothers

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## Brain Injury

### Refers to:

Asphyxia-In adequate oxygen supply prior to, during, or just after delivery.

Oxygen deprivation causing hypoxic ischemic encephalopathy (HIE)  
PVL-Periventricular Leukomalacia-most common ischemic brain injury

From an ischemic event

Arteries that supply the white matter areas of the brain are very fragile

IVH-Drop in blood pressure from early delivery/care giving etc. can cause a bleed into the ventricles of the brain

Brain tissue necrotizes causing lesions in the white matter surrounding the lateral ventricles

Bleeds are also next to the descending motor pathways

There is also indicators of disruption to neuronal migration

### Why the concern?

**HIE and PVL are associated with discoordination of the swallow/high risk of silent aspiration**

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## Brain Injury-PVL

PVL-Encephalopathy of prematurity "white matter damage"

Newborns weighing < 1500 grams or gestational age , 32 weeks

Incidence reports range from 3% to 15% of babies < 32 weeks showing evidence via HUS, up to 33% by MRI

Pathogenesis-complex multifactorial insults to as well as disruptions to the development of the white matter of the brain of the pre-term infant. Likely caused by antenatal, prenatal, and post natal exposure to conditions of hypoxia, ischemia, and infection/inflammation.

Inadequate blood supply through the long-deep vessels into the white matter, caused by changes arterial blood pressure impacting cerebral blood flow. Can be impacted by stress to the infant, infection, inflammation and genetic conditions combined with the intrinsic vulnerability of the white matter in infants. The complex impact of hypoxia and inflammation causes focal (cystic) and diffuse injury.

Identified by HUS (cystic only) MRI can identify both.

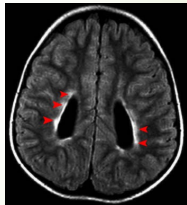
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## Brain Injury-PVL

Blood vessels



PVL lesions



OPEN PEDIATRICS

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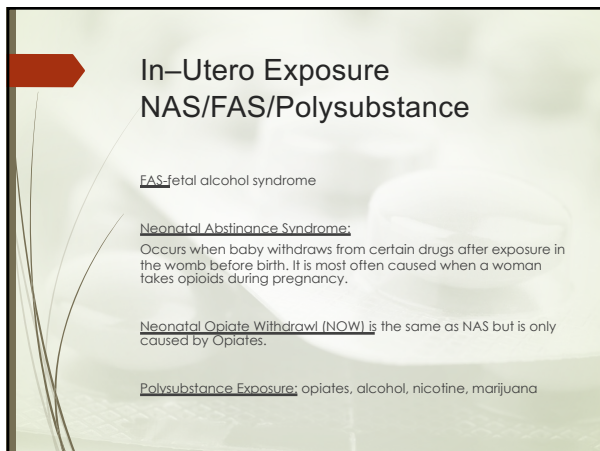
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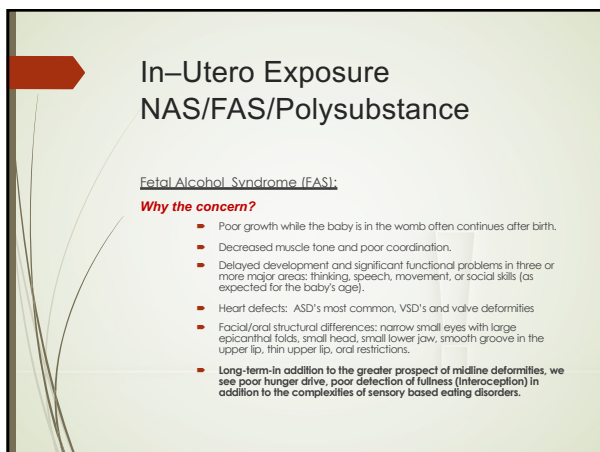
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## In-Utero Exposure NAS/FAS/Polysubstance

Neonatal Abstinence Syndrome

**Why the concern?**

- Poor in-utero growth
- >likelihood of premature birth
- > chance of birth defects

Opiates including methadone can cause significant withdrawal with some symptoms lasting > 6 months  
Cocaine-greater risk of SIDS  
Marijuana use-lower birth weight  
Nicotine-lower birth weight and >risk of poor growth

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## In-Utero Exposure NAS/FAS/Polysubstance

### NAS-symptoms of withdrawal

- Tremoring
- Irritability (excessive crying)
- Difficulty sleeping
- High-pitched crying
- Tight muscle tone
- Hyperactive reflexes
- Yawning, stuffy nose and sneezing
- Poor feeding (weak suck and poor coordination of SSB)
- GI upset (excessive spitting up, vomiting, diarrhea, terrible skin break down in diaper area)
- Poor temperature regulation
- Rapid breathing

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## In-Utero Exposure NAS/FAS/Polysubstance

Drug	Approximate time to onset of withdrawal symptoms
<b>Opioids</b>	
Heroin	24-48 hours; duration of withdrawal up to 8-10 days; earlier shorter withdrawal compared to prescription opioids
Opioids	36-72 hours; duration of withdrawal up to 10-30 days
Buprenorphine	36-60 hours; duration of withdrawal up to 28 or more days; onset maybe delayed especially with higher doses
Methadone	48-72 hours; duration of withdrawal up to 30 or more days; later onset and longer withdrawal
<b>Nonopioids</b>	
Alcohol	3-12 hours
Methamphetamines	24 hours; duration of withdrawal up to 7-10 days; can see immediate withdrawal
TCAs	24-48 hours; duration of withdrawal up to 2-6 days
SSRIs	24-48 hours; duration of withdrawal up to 2-6 days
Inhalants	24-48 hours; duration of withdrawal up to 2-7 days

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## In-Utero Exposure NAS/FAS/Polysubstance

### SSRIs/SSRAs:

About 30% of babies whose mother's take SSRI's will experience neonatal adaption syndrome

- Increased jitteriness, irritability, respiratory distress
- We have seen some babies have greater difficulty with coordination of sucking, swallowing and breathing.

([https://www.hopkinsmedicine.org/health/wellness-and-prevention/antidepressants-and-pregnancy-tips-from-an-expert#:~:text=it's%20important%20for%20a%20mother,breathing\)%2C%20among%20other%20symptoms](https://www.hopkinsmedicine.org/health/wellness-and-prevention/antidepressants-and-pregnancy-tips-from-an-expert#:~:text=it's%20important%20for%20a%20mother,breathing)%2C%20among%20other%20symptoms))

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## Neonatal Adaption Syndrome

Polysubstance  
Exposure: opiates,  
alcohol, nicotine,  
marijuana, SSRIs,  
SSRAs

The risks of combined  
substance exposures  
during pregnancy are  
poorly understood.

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## Anatomical Differences- Orofacial and Airway !

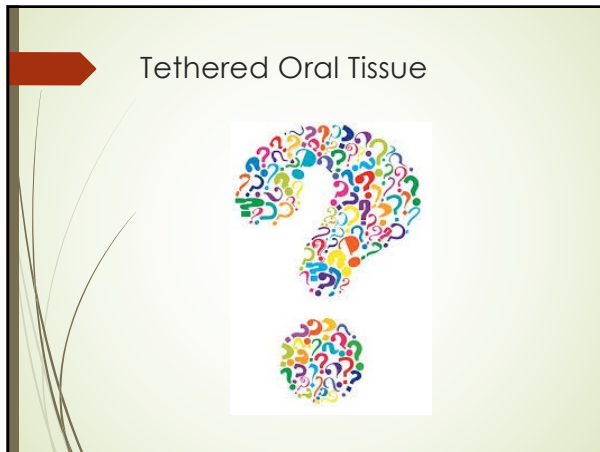
### Refers to:

- Cleft lip/palate and Pierre Robin Sequence
- Mandibular hypoplasia
- Laryngomalacia, Tracheomalacia, Bronchomalasia
- Laryngeal clefts, tracheoesophageal atresia
- Oral restrictions (tongue and lip ties)
- Macroglossia
- Severe malocclusion
- Enlarged adenoids impacting child's abilities to shift to nasal breathing during eating and drinking
- Tonsils enlarged to the point of obstructing organized transport of food through the pharynx
- Vocal fold paralysis/Dysfunction

### Why the concern?

Impact to sucking, biting chewing and/or swallow safety

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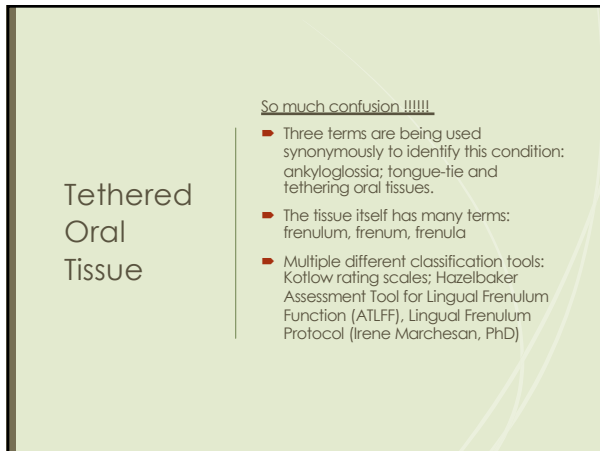
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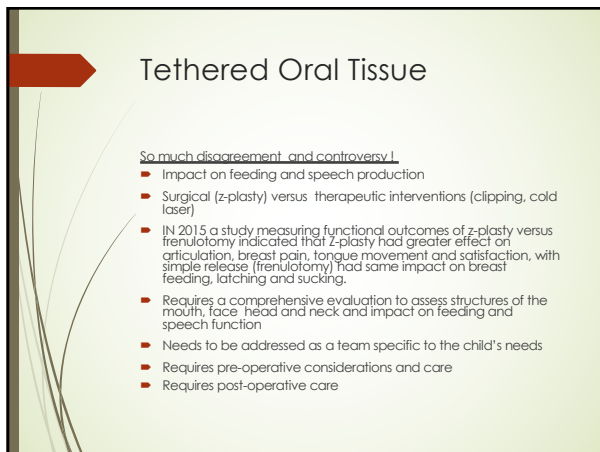
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## Tethered Oral Tissue: Impact

*Why the concern?*

**0-3 months:**

- Lip tie can impact lip seal on breast/bottle. Buccal TOTs can impact gope for latch on the breast. Tongue tie can cause the tongue to rest obstructively in the mouth impacting respiration, restrict tongue grooving around the nipple impact the transfer of milk affecting the efficiency and efficacy of sucking. It can also lead to painful breast feeding, popping off the bottle/breast to coordinate breathing and swallowing, air swallowing which then contributes to reflux.

**4-6 months**

- The infant is moving out of physiological flexion and motor control of the head, neck trunk and mouth are becoming more active (versus reflexive). With the more active sucking pattern there can be more challenge with coordinating sucking, swallowing and breathing. For spoon feeding, lingual TOTs can impact lip closure and therefore clearance of the spoon. Depending upon the location of the lingual TOTs the tongue can hump in the back, and push forward to manage the bolus, pushing it out of the mouth ("he/she does not like purees"), food can get stuck on the base of the tongue prompting gagging.

**7-9 months**

- With the increased texture/consistency of the food they can have difficulty getting thicker consistencies over the tongue base prompting gagging. Lingual TOTs can impact tongue lateralization to move food on and off the molar surfaces of the gums. Labial TOTs can impact lip closure, and seal.

Reference: Functional Assessment of TOTs by Robyn Merkel-Walsh, MS CCC SLP and Lori L. Overland MS CCC SLP C/NDT, CLC

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## Tethered Oral Tissue: Impact

*Why the concern? Indicators of functional impact*

**10-12 months**

- Rotary chewing pattern may not develop, seen as gagging, choking, vomiting and food refusal making it difficult to transition to table foods.

**13-15 months**

- May not progress with solids. There is also a risk of the child overstuffing the mouth using volume to compensate for difficulties with getting bites on and off the teeth for chewing, transporting bites back for swallowing. Labored tongue pumping can be necessary to get (un-chewed) bites over the tongue base into the throat for swallowing.

**16-24 months**

- Can still be reliant upon a primitive munch/mashing chew to break down bites. This chewing pattern is not effective for truly fibrous foods (meats, fresh fruits and vegetables).

Reference: Functional Assessment of TOTs by Robyn Merkel-Walsh, MS CCC SLP and Lori L. Overland MS CCC SLP C/NDT, CLC

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## Tethered Oral Tissue: Impact

*Why the concern? Indicators of functional impact*

**25-36 months**

- At the age for which it is expected for children to have adult oral motor plans for feeding, TOTs can impact saliva management, chewing, gagging and choking associated with food refusal, open mouth posture (can contribute to sleep disordered breathing over time), poor dental hygiene (tongue and/or lip mobility impacting the ability to clear residue from the pockets of the mouth and effectively brush teeth).

• Reference: Functional Assessment of TOTs by Robyn Merkel-Walsh, MS CCC SLP and Lori L. Overland MS CCC SLP C/NDT, CLC

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## Tethered Oral Tissue

- Determining whether or not a child is a candidate for release requires a **thorough feeding, swallowing and potentially speech evaluation (depending upon the child's age and stage)**, with complete review of background information (birth, medical and developmental history), examination of the structures. Pre-operative intervention to determine and begin to address the impact on function including range of motion; consideration into muscle tone of the oral structures, motor planning, sensory processing disorders, speech sound disorders.
- BOT: base of tongue-some of our youngsters who choking/coughing on food, we are discovering from MBSS/VFSS that food is getting so long/so much effort to get over the base of the tongue that onset of the swallow is very delayed; that the tie is interfering with tongue base retraction on action which contributes to stripping residue from the pharynx. [ 3 ]

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- Pre-feeding therapy exercises: stretches, neuromuscular education, are a step ahead of feeding goals (e.g. working on tongue lateralization ahead of chewing) and are based upon the sensory motor components of the skill the child is missing.
- When it has been thoroughly determined that the child has functional complications associated with tongue-tie that cannot be remediated with therapeutic intervention along, then it is time to proceed with a consultation with a professional with extensive background in TOTs for consideration of release.

Tethered  
Oral Tissue:  
being  
thorough,  
getting  
prepared

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## Tethered Oral Tissue: Methods of release

Needs to be based upon the findings of each child.

**Laser (light amplification by stimulated emission) release:** Often used for infants/young children. It is quick with no general anesthesia and works well for thin, anterior lingual and for tie ties. It releases the TOTs and cauterizes the tissue simultaneously with the advantage of less trauma at the surgical site and scar tissue versus frenectomy. There is no bleeding or sutures. It may not be adequate for some types of posterior tongue ties for which the incision needs to extend beyond the frenulum into the tongue or when the ankyloglossus has re-attached with a thick band of scar tissue.

**Frenectomy:** "snip", "clip" done with surgical scissors with local anesthetic. Used to get breast feeding underway in the hospital.

**Revision surgery:** anesthesia is brief (15-20 minutes) and allows for primary healing (edges of wound are held together) which supports the development of less scar tissue. Use of anesthesia is helpful for children who are not candidates to be awake. Z-plasty is the most common form which allows for precise incisions and closure of the wound in a manner that allows for lengthening of the anterior tongue.

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Tethered Oral  
Tissue:  
Wound  
Management

Purpose: To gently keep the wound open

Many On-going Debates and Different Methodologies: active wound care post laser with the goal of keeping the diamond-shape open.

Issues:

Babies can struggle with their tolerance

Parents are wary of causing aversion and skip or skimp on the wound care.

TOTs can easily re-attach if wound care is not performed/not performed enough.

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Tethered Oral Tissue: Risks

What are the risks of releases ?

- Scarring-can impact ROM (Most methods seek to limit this outcome)
- Pain-usually short and minimal
- Bleeding-should be minimal when done by a professional who frequently does this surgery
- Re-attachment: can be difficult to distinguish re-attachment from an incomplete release. An open wound will re-attach if wound management is not carried out.
- Contraindicated for children with jaw mandibular hypoplasia/pierre robin sequence

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- Decreases risk of scarring
- Decreases risk of re-attachment
- Improving functional movement of the tissue for speech and feeding.
- Children should undergo post operative therapy to put the newly released tissue into use for feeding and speech production skills, address established compensatory strategies that interfere with normal function.
- Body work: Bodywork is the use of hands-on touch and physical therapy to allow a baby's soft tissues to release tension and reorganize, is performed by a professional such as a skilled osteopath, a chiropractor (trained in craniosacral therapy and treating newborns), an occupational therapist, a physical therapist, or in some cases a highly skilled massage therapist with extensive in infants and craniosacral therapy

Tethered  
Oral Tissue:  
Follow-Up  
Therapy

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## Mandibular Hypoplasia

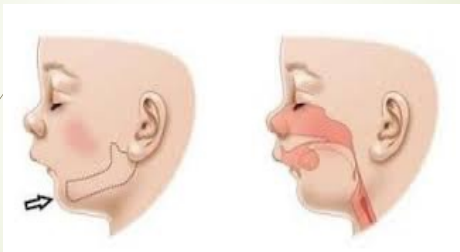
- The under development of the mandible (lower jaw)-also known as micrognathia. It can occur in isolation, linked to a genetic condition (VCFS/Digeorge syndrome, Pierre Robin Sequence, Trisomy 13 and 18,etc) and is often an outcome of FAS (we are seeing it in NAS as well).

### *Why the concern?*

- Position of the jaw causes posterior regression of the tongue which blocks the air space.
- Makes it difficult to breast and bottle feed interfering with weight gain
- Can interfere with respiration causing/contributing to apnea

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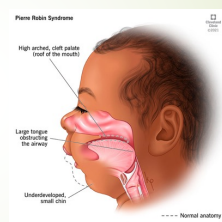
## Mandibular hypoplasia and thie impact on tongue placement



80

## Pierre Robin Sequence

A rare congenital birth defect characterized by an underdeveloped jaw, backward displacement of the tongue and upper airway obstruction. Cleft palate is also commonly present in children with Pierre Robin sequence



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## Pierre Robin Sequence

It is called a "sequence" because the initiating feature, a small undeveloped lower jaw is thought to cause a cascade of anatomical differences.

At 7-10 weeks gestation the baby's jaw grows rapidly. This allows the tongue to drop from between the halves of the palate (roof of mouth) to the floor of the mouth. If the lower jaw does not grow properly, the space is too small and the tongue is forced to the back of the mouth.

The position of the tongue can block the airway, making breathing difficult, and can prevent the palate from closing, resulting in a cleft palate.

### Why the concern?

This can significantly impact an infant's ability to suck and coordinate sucking, swallowing and breathing.

\*\* Link with a craniofacial team

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## Cleft Lip and Palate



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- The cleft may be in the baby's hard or soft palate or both. It may occur by itself or with a cleft lip. It can be unilateral (one side of the palate) or bilateral (both sides of the palate)
- Children born with cleft palate will need to be followed by a multidisciplinary craniofacial team from infancy through their teenage years depending upon the type of cleft and the possible impact on feeding, hearing, speech, dentition.
- Babies with cleft lip tend to undergo repair at 2-3 months.
- Babies with cleft palate, because the roof of the mouth is open, can have trouble with creating suction to pull milk from the nipple and breast (some babies can breast feed ! If it is a parent goal, mothers should be encouraged to try!).

## Cleft lip and palate

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## Cleft lip and palate

- The timing of repair for babies with clefts of the hard and/or soft palate depends upon multiple factors and is a team decision based upon the child's anatomy.
- Example: a child with Pierre Robin Sequence is struggling with airway obstruction, they may require another surgical repair first such as a tongue-lip adhesion or a jaw distraction surgery.
- Jaw distraction is the name for a surgical method of lengthening a small or recessed (hollow or indented) jaw.
- Working on feeding skills for children with cleft lip and/or palate may require specialized feeding equipment and strategies and therefore close coordination with and coaching from their craniofacial team.

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## Vocal fold paralysis in newborns

- Most commonly caused by iatrogenic causes due to injury of the left recurrent laryngeal nerve during cardiac surgery but also congenital or neurological disorders. Generally improve over time but.....
- **Why the concern?**
- VF closure is one of the key airway protection mechanism during swallowing. Paralysis interferes with VF closure creating significant risk of aspiration, can contribute to reactive airway disease, respiratory distress etc. making feeding and safely coordinating feeding and swallowing challenging.
- Requires close monitoring for impact on breathing and swallow safety.

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## Laryngomalacia

This is a floppiness of the larynx that causes noisiness of breathing from the cartilage of the larynx collapsing with inspiration (hallmark is inspiratory stridor).

- **Why the concern?**
- Baby is trying to take in oxygen through a narrow opening, increasing WOB and respiratory rate
- This naturally makes it more difficult for coordination of SSB
- This can lead to aspiration during feeding [77]
- Feeding is more effortful and fatiguing. This can cause challenges with weight gain and growth.
- Breathing can become very dicey with respiratory illness
- It can cause apnea
- It can contribute to reflux

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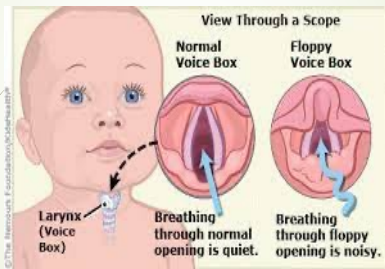
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## Laryngomalacia



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## Laryngomalacia

Indicators of more severe conditions include:

- irritability;
- poor feeding;
- pulling in of the skin at the collar bone, between the ribs, or under the ribs;
- flaring of the nose, increasing effort to breathe;
- poor weight gain or weight loss, especially in infants.
- \*\*\*\*While rare, symptoms can be confused with vocal fold paralysis, subglottic hemangioma

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## Tracheomalacia

- Cause: cartilage in windpipe did not develop properly, incurred damage or vessel is compressing
- Symptoms:
  - appear between 4-8 weeks when baby is breathing when the baby's respiratory needs create a wheezing sound. On exhalation the trachea narrows or collapses so much that it may feel hard to breathe.
  - high-pitched breathing, rattling or noisy breathing (stridor) frequent infections in the airway, such as bronchitis or pneumonia

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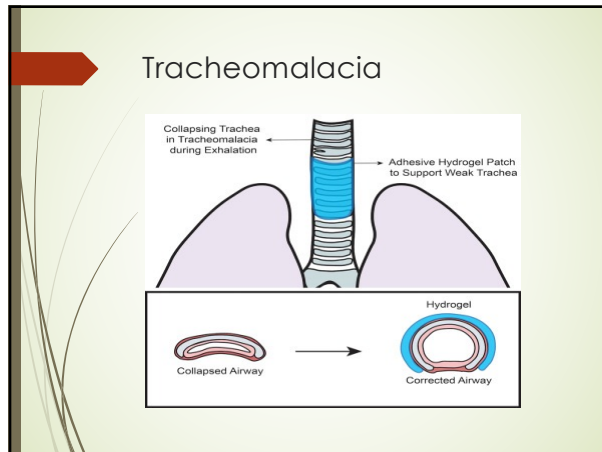
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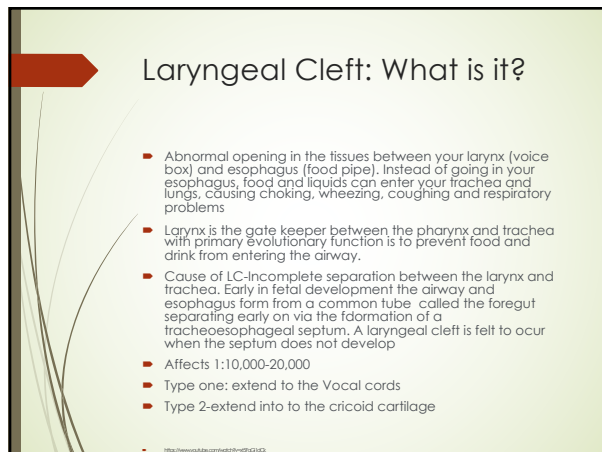
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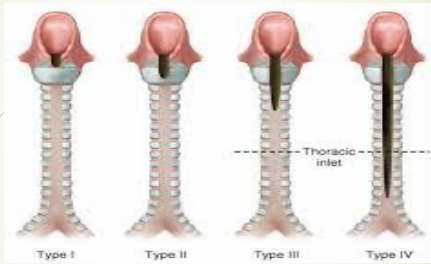
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## Laryngeal Cleft: What is it?



<https://www.youtube.com/watch?v=xt5FgGi1dCk>

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## Laryngeal Cleft

### Clinical Symptoms:

- Difficult feeding
- Cough with thin liquids
- Stridor after drinking
- Cough and wheezing

<https://www.youtube.com/watch?v=xt5FgGi1dCk>

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## Laryngeal Cleft

### Concurrent Comorbidities

- Laryngomalacia
- Tracheobronchomalacia
- GERD
- Other congenital conditions

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## Laryngeal Cleft

To date, genetic conditions frequently associated with laryngeal cleft

- Opitz Fries syndrome
- Pallister Hall syndrome
- VACTERL association
- CHARGE syndrome

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## Laryngeal Cleft

Send to an Aerodigestive Team

Mild symptoms

- Feeding therapy
- Anti-reflux treatment
- Thickened feeds to manage aspiration

Moderate symptoms

- Medically optimize-manage swallowing disorder, treatment
- Gel repair and surgical repair

[ 41,90 ]

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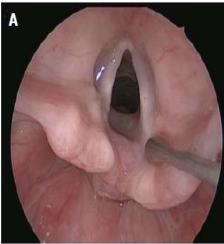
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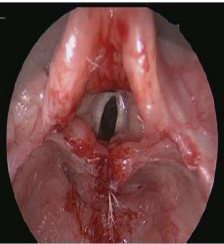
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## Laryngeal Cleft

**A**



**B**



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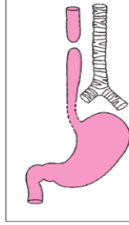
## TEF/EA

## TYPES OF TRACHEOESOPHAGEAL ANOMALIES

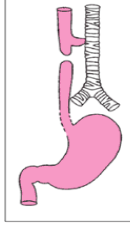
Congenital malformations of the esophagus occur in about 1 in 4,000 live births. The American Academy of Pediatrics classifies the anatomic variations of tracheoesophageal anomalies as follows:

- Type A (7.7%): esophageal atresia without fistula
- Type B (0.8%): esophageal atresia with tracheoesophageal fistula to the proximal segment
- Type C (86.5%): esophageal atresia with fistula to the distal segment
- Type D (0.7%): esophageal atresia with fistula to both segments
- Type E (or H-Type) (4.2%): tracheoesophageal fistula without atresia

TYPE A



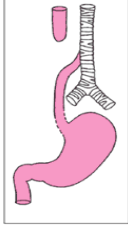
TYPE B



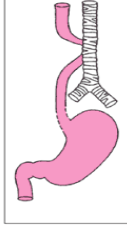
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## TEF/EA

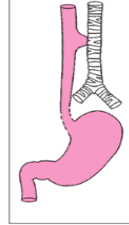
TYPE C



TYPE D



TYPE E



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## TEF/EA

**Why the concern?**

- Motility disorders of the esophagus are almost universal whenever there is esophageal repair.
- At the site of surgical repair anastomosis (connection between two passageways) there is scar tissue. This can build and create a stricture that can prevent flow of food and drink.
- There is a high risk of GERD from dysmotility. This can lead to aspiration related illnesses.
- Progressing feeding skills needs to be done with incredible care, understanding of the child's surgery
- [ 45,47 ]

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## TEF/EA

### *Why the concern?*

- Progressing feeding skills needs to be done with incredible care, understanding of the child's surgery, sites of possible stricture, signs of stricture.
- This conditions can co-exist with others. We need to be watchful of swallow safety for liquid (i.e. we have found undetected laryngeal clefts later)
- To move these children onto solid food their chewing skills need to be thorough-there's no room for error. Un-chewed/insufficiently chewed pieces can get stuck.
- Oftentimes food needs to be "chased" with liquid in order to successfully travel through the site of anastomosis. How this is done needs to be determined via MBSS/VFSS.

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## Systems and possible system Interactions

Respiration-Digestion-Cardiac-  
Neuromotor-Sensory Motor

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## The Airway

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## The airway: Prior to feeding

- Is the child able to shift to nasal breathing when his/her mouth is closed? If not, what are the possible causes?
- What is the child's resting respiratory rate? Is it regular/irregular? Evidence of effortful breathing?
- Vocal quality: clear? congested? Gurgly on and off? Coughing on own secretions?

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## The airway.....

Respiratory rate: breaths per minute

Age	Resting respiratory rates (breaths per minute)
Normal Infant	30-40
Premature Infant	40-60
sick Infant	60-80
1-2 year old	25-30
7-8 year old	20-25
10 year old	20
18 year old	16-20

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## The airway.....

Heart rates

AGE	Resting Heart Rates (beats per minute)
10 weeks to 2 years	120-140
2 years	110
6 years	100
10 years	90
Adolescence	60-80

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## The airway....while eating and drinking

- Child's respiratory rate at rest? while eating ? while drinking ?
- Apnea ?
- Changes with voice quality while eating and drinking- stridor, gurgle, congestion
- Color change, cough, true choke, persistent throat clearing

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## The airway: coordination of swallowing and breathing

How does the child meet breathing needs during eating ?  
Drinking ?

- Able to shift to nasal breathing while eating and drinking ?
- Able to take brief pauses to breath ?
- Effortful breathing ?
- Turning away from food/feeding equipment, popping off the breast/bottle or emptying mouth to breath ?

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## Respiratory Conditions

### 1 Refers to:

- BPD/CLD
- RDS (Respiratory Distress Syndrome)
- Need for ventilator dependence-ECMO
- Unexplained asthma

### Why the concern?

Higher RR creates natural challenges with coordination of sucking, swallowing, and breathing.

### 2 Refers to:

- Unexplained asthma
- Frequent respiratory illnesses, year-round, including:
  - Pneumonias
  - Bronchitis
  - "always has a cold"
  - Unexplained fevers

### Why the concern?

Can indicate aspiration

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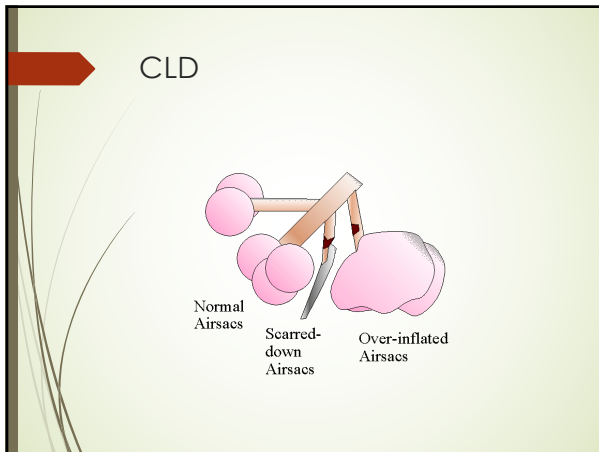
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**ECMO: Extracorporeal Membrane Oxygenation**

- ECMO is a form of life support used for babies, children and adults with life-threatening heart and / or lung problems. ECMO provides time for the body to rest and recover by doing the work of the heart and lungs.
- <https://www.youtube.com/watch?v=SHuA7E1WzHI>

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**ECMO: Extracorporeal Membrane Oxygenation**

If is advanced life saving technology, a long-term support, used for infants and children experiencing the below conditions who have not responded to maximal ventilatory support:

- Asphyxia
- Meconium aspiration syndrome
- RDS
- Group B Streptococcal sepsis
- Congenital diaphragmatic Hernia (DH)
- Sometimes needed post cardiac repairs
- Children awaiting cardiac transplant

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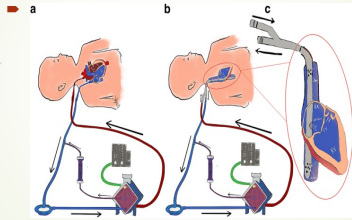
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## ECMO: Extracorporeal Membrane Oxygenation



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## ECMO: Extracorporeal Membrane Oxygenation

### Why the concern?

- High rate of feeding and swallowing disorders following ECMO including: incoordination of suck and swallow; frequent regurgitation and emesis; gastroesophageal reflux; delayed gastric emptying, and slow transit; swallowing disorders.
- It is difficult to distinguish to what degree these are linked to the underlying condition necessitating ECMO versus a side effect of ECMO use.
- Some knowns:
- Vocal cord dysfunction; intestinal dysmotility in infants surviving with the use of ECMO

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## Examples of impact of respiratory disorders on feeding

- RR > 60 can naturally impact coordination of sucking, swallowing and breathing.
- Children with high RR and/or significant work of breathing (e.g. laryngomalacia, tracheomalacia)
- 65% of patients with severe laryngomalacia have reflux. Further analysis revealed that those children with moderate to severe laryngomalacia were nearly 10 times more likely to suffer from reflux than those with only mild laryngomalacia.
- The proposed mechanism is that aerophagia during feedings causes gastric distention leading to vagal reflexes followed by postprandial vomiting and regurgitation.

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## Cardiac Conditions

### Refers to:

heart conditions including but not limited to:

- PDA
- ASD
- VSD

### **Why the concern?**

Impact to infant's/child's energy and therefore feeding efficiency, weight gain and growth. This can be problematic if there is a weight goal to proceed with surgery.

Some of these children have co-existing midline differences to the structures of their airway.

Sometimes swallowing difficulties signal a heart difference (e.g. esophageal compression from an aberrant subclavian artery).

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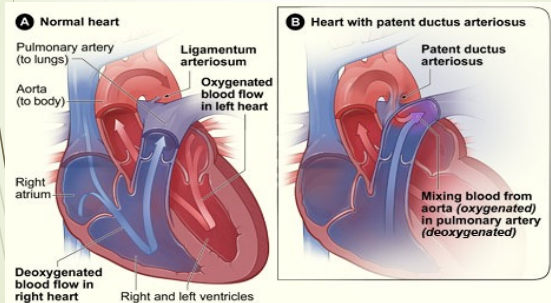
## Cardiac Conditions: PDA

### Patent Ductus Arteriosus

- Before birth, the two major arteries—the aorta and the pulmonary artery—are connected by a blood vessel called the ductus arteriosus. This vessel is an essential part of fetal blood circulation. At birth, the vessel is supposed to close as part of the normal changes occurring in the baby's circulation.
- In some babies, however, the ductus arteriosus remains open (patent). This opening allows oxygen-rich blood from the aorta to mix with oxygen-poor blood from the pulmonary artery. This can put strain on the heart and increase blood pressure in the lung arteries.

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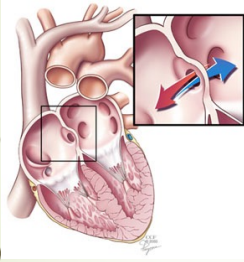
## Normal heart versus PDA



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### Cardiac conditions: ASD



**ASD-Atrial Septal Defect:**  
An ASD is an opening in the atrial septum, or dividing wall between the two upper chambers of the heart known as the right and left atria. ASD is a congenital (present at birth) heart defect. As the fetus is growing, something occurs to affect heart development during the first eight weeks of pregnancy, resulting in an ASD. An atrial septal defect allows oxygen-rich (red) blood to pass from the left atrium, through the opening in the septum, and then mix with oxygen-poor (blue) blood in the right atrium.

[www.chkd.org/HealthLibrary/](http://www.chkd.org/HealthLibrary/)

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### Cardiac Conditions: VSD

#### VSD

- VSD opening in the ventricular septum/dividing wall between the two lower chambers of the heart allowing oxygen-rich (red) blood to pass from the left ventricle through the opening in the septum, and then mix with oxygen-poor (blue) blood in the right ventricle.

#### Typically

- Normally, oxygen-poor (blue) blood returns to the right atrium from the body, travels to the right ventricle, then is pumped into the lungs where it receives oxygen. Oxygen-rich (red) blood returns to the left atrium from the lungs, passes into the left ventricle, then is pumped out to the body through the aorta.

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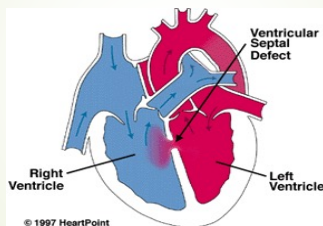
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### Schematic of a VSD



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## Examples of Impact of Cardiac Disorders on Other Feeding Systems

Inefficient heart function can cause:

- Increased respiratory rate in an effort to meet oxygen needs of the body, naturally disrupting coordination of sucking, swallowing and breathing.
- The child to burn more calories trying to take in calories.
- Fatigue/poor endurance from the heart condition.
- Delayed gastric emptying
- \*people born with CHD have about a 33-percent increased likelihood of being diagnosed with Autism spectrum disorders.  
(<https://answers.childrenshospital.org/autism-and-heart-disease-genetic-connection/>)

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## Cardiac Conditions: Aberrant Subclavian Artery



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## Digestive System Conditions



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## Conditions of the digestive system

### Refers to:

- Gastroesophageal reflux
- EoE
- FPIES
- CDH (congenital diaphragmatic hernia)
- Short Bowel Syndrome
- Chronic constipation/diarrhea

### **Why the concern?**

The above conditions, typically under the care of a gastroenterologist, often require teaming up between PCP, GI MD, feeding and swallowing and nutrition support to manage.

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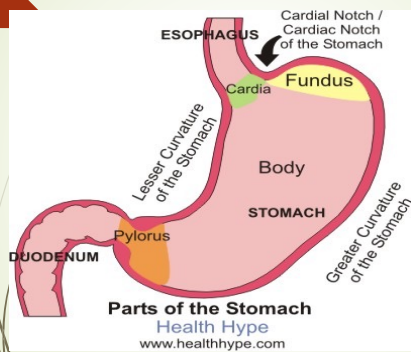
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## Parts of the stomach



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## Digestion: GERD-some of the types

### ■ GER-Gastroesophageal reflux

#### ■ Acid reflux:

[www.youtube.com/watch?v=o8ShP84HP4](http://www.youtube.com/watch?v=o8ShP84HP4)

Sandifer's Syndrome:

[www.youtube.com/watch?v=JU2XK0-8Ap0&feature=related](http://www.youtube.com/watch?v=JU2XK0-8Ap0&feature=related)

- Delayed gastric emptying
- Eosinophilic Esophagitis
- [www.youtube.com/watch?v=UbVTG2RauvM&feature=related](http://www.youtube.com/watch?v=UbVTG2RauvM&feature=related)
- A combination of these

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## Digestion: GERD-some of the types

- Reflux in infants
  - GER: Physiologic reflux/Gastroesophageal reflux-occurs post feedings ("post prandially") is short lived, asymptomatic and rarely occurs during sleep. Common causes: over feeding, air swallowing, crying, coughing. Occurs during transient relaxation of the LES which allows stomach contents to travel up the esophagus. "Happy spitters"
  - peaks at 4 months of age, and tends to resolve with time

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## Digestion: GERD-some of the types

- Reflux in infants
  - GERD: Gastroesophageal Reflux Disease-highly misunderstood symptoms of mucosal damage caused by stomach acid rising from the stomach into the oesophagus. GERD is associated with a range of adverse respiratory, gastrointestinal, and neurobehavioral effects. Adverse effects may include pain, wheezing, apnea, stridor, recurrent bronchiolitis, episodes of oxygen desaturation, aspiration pneumonia, swallowing dysfunction, frequent vomiting, choking and gagging, lower energy intake and excessive weight loss, disorganized and dysfunctional sucking or swallowing, delayed readiness for solid foods or food refusal and delayed development.

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## Digestion: GER and GERD

- Determination of the exact prevalence of GER versus GERD is challenging because there is unclear demarcation between physiologic and pathologic reflux and incidence and prevalence data
- Our job: If we see reflux is getting in the way of pleasurable feedings, is painful, causing airway invasion, associated with poor weight gain and growth, we need to help the parents communicate this clearly and effectively to the PCP so that action is taken.

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## Examples of impact of GERD on other systems

- Acid reflux can cause chest pain, coughing, wheezing, inflammation of the vocal cords when GERD leads to micro/macro aspiration. This can cause symptoms like asthma.
- The supraglottic mucosa must be able to sense the upcoming food bolus. This sensation leads to appropriate vocal fold closure, while also stimulating the opening of the hypopharynx and upper esophageal sphincter. Edema from chronic irritation by can cause decreased sensation in these tissues, for airway protection, and thereby increases the risk of aspiration in these patients.

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## Digestion: Gastric Emptying (GE)

- Gastric emptying: a measure of the speed of delivery of gastric contents into the duodenum. It is measured in half time- the time required by the stomach to empty 50% of the ingested meal. This is the simplest way to assess gastric transit.
- Typical gastric emptying time for the average gastric half-emptying time for meals of human milk was 48 min, and for meals of infant formula 78 min. After 1 hour an average of 29.5 ml of human milk and 22.7 ml of infant formula per 0.1 m<sup>2</sup> of body surface area had emptied from the stomach.

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## Digestion: GE

- Breast milk has a faster GE than formula milk.
- Formulas: there is a trend towards whey feeds emptying faster, different methodologies, feed compositions and patient groups makes it difficult to draw firm conclusions.
- This can result in a roulette of formula changes !!!

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## Digestion: GE in premature infants

- Gastric emptying is controlled by motor activity in the antrum and the duodenum. Antral motor activity is similar in preterm and term infants, but duodenal motor patterns significantly differ.
- Gastric emptying is also modulated by physical characteristics of the nutrient ingested, such as pH, osmotic load, and specific nutrient content. It is not known if caloric density or rate of feeding alter duodenal motor activity in preterm infants.

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## Digestion: EoE

- Eosinophilic Esophagitis: allergic condition that happens in the esophagus most commonly associated with food. The esophagus becomes inflamed and does not contract properly. It can get narrowed and develop rings or abscesses. The symptoms happen when your immune system makes white blood cells in reaction to an allergen.
- Common symptoms: (From Boston Children's Hospital Website)
  - difficulty swallowing (dysphagia)
  - food getting stuck in the throat (impaction)
  - chest pain
  - Vomiting
  - poor weight gain
  - refusing to eat (especially in toddlers)
  - increased sensitivity to food texture

\*none of these symptoms points definitively to eosinophilic esophagitis and many of the symptoms can overlap with other conditions such as gastroesophageal reflux disease.

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## Digestion: EoE

### Foods Commonly Associated:

- milk and other dairy products
- wheat
- eggs
- soy
- peanuts
- tree nuts
- fish, and shellfish.

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## Digestion: EoE

EoE is a chronic condition, the vast majority of children are able to eliminate their symptoms simply by avoiding the foods that trigger them.

### Medical Approaches:

- Dietary modifications: Avoiding foods indicated by allergy testing; elimination diet (avoiding most common allergens); strict elemental diet (specialized formula)
- Medications: acid blocking medications, topical medications

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## Digestion: EoE: Examples of Impact on other systems

" Judy I have froggies in my throat because my drinks are going the wrong way"

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## Food protein-induced enterocolitis syndrome (FPIES)

- Acute FPIES presents with repetitive, profuse vomiting that typically starts one to four hours after a triggering food is eaten. Some infants can become floppy, pale, cold and develop diarrhea.
- Chronic FPIES is uncommon, and usually occurs in infancy, due to repeated exposure to a food trigger (usually cow's milk protein or soy). It presents with persistent vomiting and/or diarrhea (which can result in poor weight gain over time). If the trigger is reintroduced before the condition is outgrown, an acute FPIES reaction can occur.
- The primary treatment is strict avoidance of the triggering food. Most children outgrow FPIES by age 3 or 4

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## Short gut/Short bowel syndrome

- Short bowel syndrome is a condition in which the body cannot absorb enough nutrients from foods because part of the small intestine is missing or damaged. The small intestine is where most of the nutrients you eat are absorbed into your body during digestion.
- Common causes: malrotation; necrotizing enterocolitis

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## Congenital Diaphragmatic Hernia CDH

- Congenital diaphragmatic hernia (CDH) is a rare condition that occurs when the diaphragm – the muscle that separates the chest from the abdomen – fails to close during prenatal development. This allows abdominal organs (stomach, intestines, and/or liver) to move into the chest. When the abdominal organs are in the chest, they can crowd the heart and lungs and keep the lungs from growing normally.
- When a baby has CDH, their lungs will be smaller than expected (pulmonary hypoplasia), and will have less developed blood vessels. This causes high blood pressure in the lungs (pulmonary hypertension).

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## Constipation: Common causes

- Poor fluid intake (fearful of drinking)
- Diet is low in fiber
- Cow's milk allergy
- Neurological disorder: low, high or fluctuating muscle tone
- Side effect of some medications
- More rarely an anatomical difference in the lower digestive system, metabolic condition, etc.

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## Constipation: Possible Impact on other systems

- Hunger drive-can cause abdominal bloating, cramps or pain leading to decreased appetite.
- Withholding of stool (because it hurts to poop).
- GER-The LES constricts in order to prevent the flow of stomach contents upward into the esophagus, stopping reflux. However, if the pressure in the abdominal cavity is greater than the forces of the LES, such as with constipation, the LES cannot fully close and reflux occurs.
- Constipation takes up a large amount of space in the abdomen, which often leads to dysfunction of the bladder. This can cause incontinence, urgency of urination, frequency of urination or a sensation of having to urinate when there is little or no urine to urinate.

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## Autism Spectrum Disorders (ASD)



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## Autism Spectrum Disorders (ASD)

### Why the concern?

- Impaired sensory modulation (extremes in sensory seeking and sensory avoidance) may have impacted the child's ability to engage in the developmental sensory exploration needed for sensory learning about foods.
- GI disorders: acid reflux; EoE; chronic constipation
- Extensive oral sensori-motor differences such as challenges with coordination of: sucking, swallowing and breathing for drinking; chewing.
- Pharyngeal phase swallowing disorders linked to discoordination, anatomical differences such as laryngeal cleft, etc.
- Esophageal phase swallowing disorders (linked to EoE, dysmotility, etc.).

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## Genetic Conditions with **high incidence** of Feeding and Swallowing Disorders

The pace of gene discovery for autism and other neurodevelopmental disorders is rapid.

Examples:

- Angelman's Syndrome-sucking, chewing and swallowing.
- Cornelia de Lang Syndrome (CdLS)-difficulty with chewing, swallowing, pharyngeal peristalsis, esophageal peristalsis, GERD
- CHARGE: coloboma, heart defects, atresia choanae (also known as choanal atresia), growth retardation, genital abnormalities, and ear abnormalities
- Down syndrome-**Dysphagia**, 2016 Oct;31 (5):663-71. doi: 10.1007/s00455-016-9725-7. Epub 2016 Jul 12. of 158 children, 60% aspirated and 91% of these aspirated silently

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## Genetic Conditions with **high incidence** of Feeding and Swallowing Disorders

The pace of gene discovery for autism and other neurodevelopmental disorders is rapid.

Examples:

- Russell-Silver Syndrome-FTT, feeding and swallowing
- Velocardiofacial/Digeorge syndrome, e-nasopharyngeal reflux, silent aspiration, cricopharyngeal dysfunction
- VACTERL: vertebral defects, anal atresia, cardiac defects, tracheo-esophageal fistula, renal anomalies, and limb abnormalities

**Why the concern?**

Multisystem involvement= multiple possible contributing causes for feeding, swallowing, nutrition and growth concerns. All children with these conditions should have a feeding and swallowing and nutrition evaluation to rule out concerns

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## Neuromotor Conditions

Refers to:

- Cerebral palsy, muscular dystrophies, leukodystrophies, mitochondrial disorders
- "The pace of gene discovery for autism and other neurodevelopmental disorders is rapid,"

**Why the concern?**

- Challenges with tone, weakness and sensation impacting effective and efficient biting, sipping and coordination of chewing. Risks can change with growth.
- Discoordination of the swallow. HIGH incidence of silent aspiration.
- May be progressive.

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### Neuromotor Conditions:

examples of impact on other systems

- Postural stability to support the head, neck, trunk, shoulder girdle and pelvis for effective upright stability and respiration to support sufficient breathing and safe swallowing etc.
- > 85% incidence of digestive disorders (GERD, constipation, etc.)
- Drooling-loss of saliva management, impact on swallow safety and hydration.
- Functioning of their respiratory system - poor respiratory volumes with insufficient strength to cough to clear.
- Gross and fine motor impact on self feeding skills-e.g. don't have the precision to insure appropriate bite size, place foods in a safe spot in their mouth, etc.

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### Oral Sensory Motor Conditions

- Disorders of sucking, swallowing, breathing, sipping sipping, biting, chewing and swallowing impacting weight gain, growth, swallow safety.
- Bottle and breastfeeding aversion
- Gagging on purees
- Gagging and choking on solid food
- Extreme food selectivity

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### Oral Sensory Motor Conditions:

Examples of impact on other systems

- Insufficient liquid intake from challenges with efficiency and/or safety impacting hydration, contributing to constipation, challenges with alertness, etc.
- Challenges with coordination of sucking, swallowing and breathing, leading to aspiration/fear of aspiration.
- Reduced sensation impacting a child's abilities to detect appropriate bite size, when to chew, how long to chew so that food is safely swallowed.
- Poor chewing skills causing gagging and choking events, leading to food aversion and/or fear to practice needed skills.
- Discoordination leading to air swallowing causing reflux.
- And many more.....

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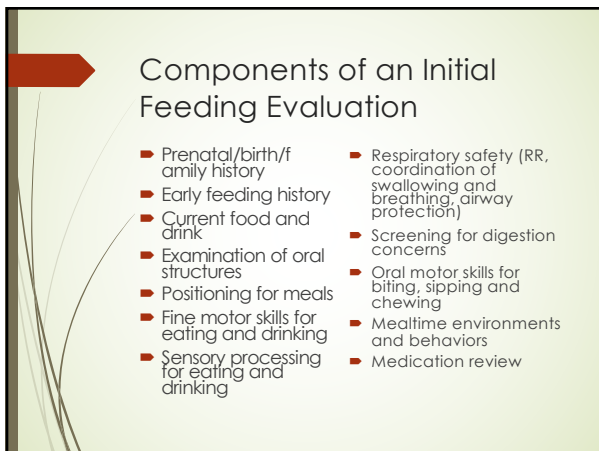
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- Prenatal/birth/family history
- Early feeding history
- Current food and drink
- Examination of oral structures
- Positioning for meals
- Fine motor skills for eating and drinking
- Sensory processing for eating and drinking
- Respiratory safety (RR, coordination of swallowing and breathing, airway protection)
- Screening for digestion concerns
- Oral motor skills for biting, sipping and chewing
- Mealtime environments and behaviors
- Medication review

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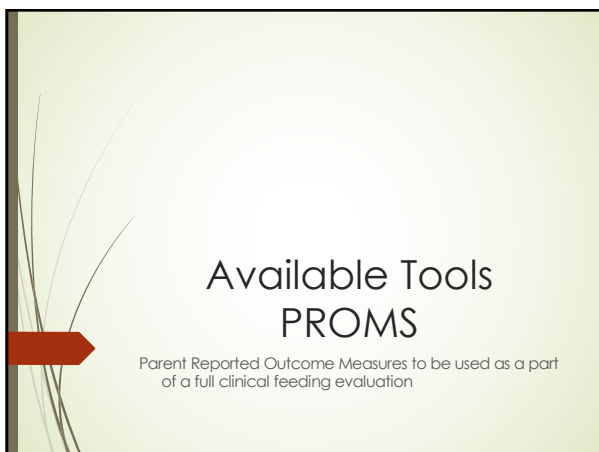
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## Available Tools PROMS

Parent Reported Outcome Measures to be used as a part of a full clinical feeding evaluation

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## For parents of infants

### Neo-EAT

Tool for parents of infants birth to 7 months of age.

There is a version for breast feeding, bottle feeding and "mixed" (breast and bottle fed). It supports the clinician to complete a scoring summary and then has reference values that determine the level of concern.

Available to you through Feeding Flock

<https://feedingflockteam.org/> [ 58, 59 ]

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## Neo-EAT: Areas Targeted

- Infant Regulation
- Energy & Physiology
- Gastrointestinal Tract Function
- Sensory Responsiveness
- Feeding Flexibility

Scoring summary links to level of concern with reference values available for infants 0-2 months old, 2-4 months of age, 4-6 months, 6-7 months.

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## For caregivers of children 6 months through 7 years

- **CHOMPS (Child Oral and Motor Proficiency Scale (chOMPS))**-for children being offered solid food. It is intended to be completed by a caregiver that is familiar with the child's typical eating and movement abilities.

Available to you through Feeding Flock

<https://feedingflockteam.org/>

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## CHOMPS: Areas Targeted

- Complex Movement patterns
- Basic Movement patterns
- Oral-Motor Coordination
- Fundamental Oral-Motor Skills

Scoring summary links to level of concern with reference values available for infants 6-9 months, 9-12 months, 12-15 months, 15-18 months, 18-24 months, 2-2.5 years, 2.5-3 years, 3-4 years, 4-5 years, 5-6 years, 6-7 years,

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## For caregivers of children 6 months through 7 years

- **PediEAT**-assess observable symptoms of problematic feeding in children between the ages of 6 months and 7 years old who are being offered some solid foods.

Available to you through Feeding Flock  
<https://feedingflockteam.org/> [ 61 ]

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## PediEAT: Areas Targeted

- Physiological symptoms: examples: facial coloring, coughing, food/liquid coming out of nose, shortness of breath, tilting head back while eating (etc.)
- Problematic Mealtime Behaviors
- Selective/Restrictive Eating
- Oral Processing

Scoring summary links to level of concern with reference values available for infants 6-9 months, 9-12 months, 12-15 months, 15-18 months, 18-24 months, 2-2.5 years, 2.5-3 years, 3-4 years, 4-5 years, 5-6 years, 6-7 years,

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## Tools for measuring impact of PFD on families

### Family Management Measure of Feeding (FaMM Feed)

FaMM is intended to assess how a family is managing their child's feeding challenges. The FaMM Feed can be used with families of children between the ages of birth and 18 years old.

Available to you through Feeding Flock  
<https://feedingflockteam.org/>

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## Tools for measuring impact of PFD on families

### Feeding Impact Scales (Feeding Impact)

- intended to assess the impact of a child's feeding on the parent and family. The Feeding Impact Scales can be used with families of children between the ages of birth and 18 years old.

Available to you through Feeding Flock  
<https://feedingflockteam.org/>

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## Feeding Impact Scales (Feeding Impact)

### Sample questions:

- We have to plan ahead when eating somewhere other than our home.
- Other caregivers (grandparents, babysitters) have difficulty feeding my child.
- My child's feeding care affects my family financially.
- There is more stress in my family because of my child's feeding.
- Family members do not want to watch my child because of his/her feeding needs
- My family avoids social activities due to my child's feeding needs.
- Scores are totaled to determine total family and total parent impact

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## The GIGER (Gastrointestinal and Gastroesophageal Reflux) Scale

- The GIGER is intended to assess observable symptoms of gastrointestinal distress and gastroesophageal reflux in children under 2 years of age. The GIGER is intended to be completed by a caregiver that is familiar with the child's typical behavior.

Available to you through Feeding Flock  
<https://feedingflockteam.org/>

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## Instrumental Evaluation of the Swallow

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### Cervical Auscultation-Screening!

Aspects of Swallow Examined	Advantages	Limitations
Detects changes in upper aerodigestive tract sounds that occur during breathing, swallowing, passage of bolus	Easy, non-invasive, No radiation Swallow can be sampled over time Uses "real food"/no contrast	Does not view swallow mechanism directly, limited ability to detect aspiration events, does not define "reason" for dysphagia, correlation between sounds and swallowing events unknown

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### Questions I ask when using CA as a screening tool

- Congestion after the saliva swallow ?
- Congestion with swallowing food ? drink ?
- Most likely to occur at a what point in the meal/snack ?
- Effect of feeding position on congestion ? Equipment ?

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### Possible Benefits of CA

- As a screening tool for safe swallowing of saliva, medications, food and drink.
- Can define questions for a swallow study.
- Can contribute to swallow study design.
- When a swallow study has determined the source of congestion, it can be a monitoring/trouble-shooting tool during meals/snacks.
- Breast feeding: is the child really transferring milk?

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### When is a swallow study necessary ?

#### Medical Criteria:

- Significant pre/peri/post natal risk factors (polyhydramnios, asphyxia)
- Respiratory conditions suggesting swallowing difficulties: recurrent pneumonias, bronchitis, asthma with no other identified cause; chronic congestion; frequent unexplained low grade fevers.
- Feeding related: congestion, coughing, gurgly voice quality, stridor; RR>60; apnea or bradycardia spells, dusky coloring
- High risk neurological condition (PVL, HIE)
- Unusual patterns of feeding aversion
- Significant concern from the PCP/specialty care physician

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## How Are Swallow Studies Designed ?

- Goals are developed from clinical evaluation and/or day to day observations (e.g. sneezing, coughing, congestion, refusal of certain consistencies of food; balanced with ALARA)
- Where in mealtimes do symptoms occur ?
- Selection of food and drink.
- What do we need to do to replicate a typical meal time ?
- What do we need to do to help the child (and parent) to participate comfortably ?

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## How can you contribute? The Swallow Study Plan: part I

- **Child:** **DOB:**
- **Ordering Physician:**
- **Requesting Therapist:** Your name and contact information.
- **Scheduling considerations** (child's natural eating times, naptimes, when well vs ill, parent/family schedule):
- **Diagnoses and Statement of Feeding Safety Concerns/Questions:**

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## How can you contribute? The Swallow Study Plan: Part 2

- **Goal (s) of study:**
- Critical information needed:
- If there is opportunity:
- **Design of study:** (prioritized food/drink, sequence of presentation and rationale; sensory processing and/or motor considerations, fatigue ? )
- **Child/family considerations in study design and implementation:**
- **Positioning needs:** (orientation (s) for eating and drinking, representative of body alignment, child comfort, strategies to promote safety, equipment):
- **Food and drink needed and who is providing:**
- **Instructions given to family:**

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How can you contribute?  
Preparing the child and family

- Think through the food, drink and how it can be presented-from the child's perspective (contrasting disguised, openly discussed, etc.)
- Prep the parent and practice:
  - Avoid "yes"/"no" questions
  - Keeping child's head and neck in midline
  - Entertainment ?
  - Motivators

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How can you contribute?  
Preparing the child and family

Prepare the child:

- Practice positioning options
- Request a field trip with a snack
- Based upon the child's age, feeding/developmental status and temperament determine how to explain the study

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Sample social story

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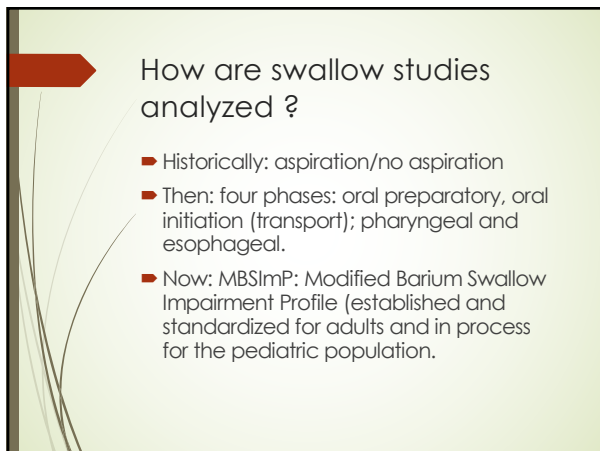
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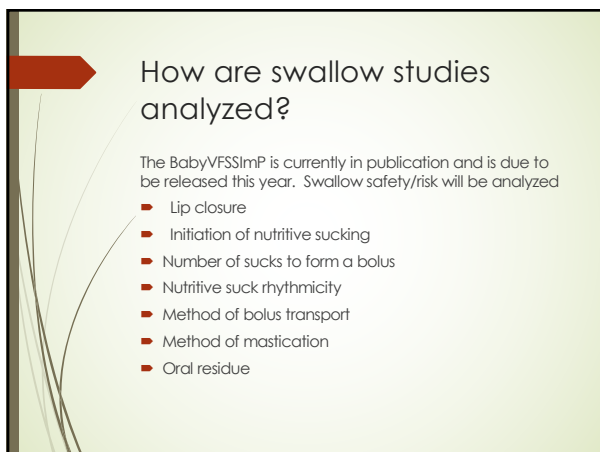
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## How are swallow studies analyzed?

- The BabyVFSSImP is currently in publication and is due to be released this year. Swallow safety/risk will be analyzed
  - Bolus location with initiation of the swallow
  - Palatal-pharyngeal approximation
  - Epiglottic movement
  - Tongue base retraction
  - Pharyngeal stripping wave
  - Vallecula residue
  - Pyriform sinuses residue

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## How are swallow studies analyzed?

- The BabyVFSSImP is currently in publication and is due to be released this year. Swallow safety/risk will be analyzed
- Early LV closure
  - Late LV closure
  - Timing of airway entry
  - Amount of penetration
  - Amount of aspiration
  - Frequency of aspiration
  - Pharyngeal esophageal segment
  - Esophageal clearance

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## FEES in Infants

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| <ul style="list-style-type: none"> <li>■ Criteria</li> <li>■ 37-40 weeks gestation</li> <li>■ Neurobehaviorally stable infant</li> <li>■ Concern for persistent /aspiration</li> </ul> | <ul style="list-style-type: none"> <li>■ Uses</li> <li>■ ? Laryngomalacia</li> <li>■ Neurogenic conditions (HIE)</li> <li>■ Question of structural differences</li> <li>■ Genetic conditions with high incidence of silent aspiration</li> <li>■ Can be done while breast feeding</li> </ul> |
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Implement swallow study and clinical findings to keep children safe at home, school and childcare

How do we ?

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Implementing the Special Dietary Medical Form & Safe Eating Plans

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Medical, educational vs life

Nutrition is the bridge to support the whole child

Inadequate nutrition or hydration may contribute to learning difficulties in school including, but certainly not limited to:

- reduced concentration
- low energy levels
- poor stamina
- difficulties problem-solving
- poor frustration tolerance

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**What is a Safe Eating Plan?**

A safe eating/safe feeding plan is a guide to how to safely and efficiently help a child or student meet their nutrition and hydration needs in the context of dysphagia, food allergy, children with metabolic differences

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**Thinking it through for each child.**

- Why does the child need a safe eating plan?
- Is there a swallowing disorder? What are the findings from an instrumental evaluation of swallow safety?
- What are key observations from a clinical evaluation of a student's eating and drinking skills?
- Are there environmental considerations for snacks and meals?
- How should food be presented?
- How should liquids be presented?
- What level of support and/or supervision does the student require?

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**Accommodating Special Dietary Needs in School Nutrition Programs**

- The Americans with Disabilities Act (ADA) Amendments Act of 2008 made important changes to the meaning and interpretation of the term "disability" under the ADA and under Section 504 of the Rehabilitation Act of 1973.
- These changes were intended to make it easier for individuals to establish that they have a disability. Most physical and mental impairments will constitute a disability.
- "Therefore, rather than focusing on whether or not a student has a disability, schools should focus on working collaboratively with parents to ensure an equal opportunity to participate in the school meal programs and receive program benefits."—USDA



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## USDA position on Special Diets

The U.S. Department of Agriculture's school meal programs aim to provide all participating children, regardless of background, with the nutritious meals and snacks they need to be healthy.

**Consistent with federal law and program regulation, this includes ensuring children with disabilities have an equal opportunity to participate in and benefit from the programs**

- National School Lunch Program (NSLP)
- the School Breakfast Program (SBP)
- the Fresh Fruit and Vegetable Program (FFVP)
- the Special Milk Program (SMP)
- the afterschool snack component of the NSLP

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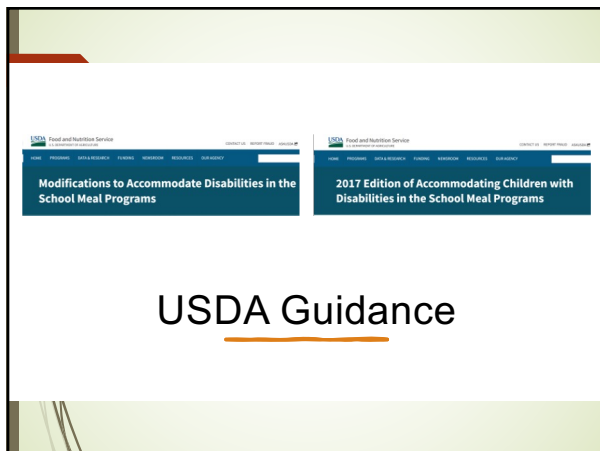
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## USDA Guidance



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## NH SMP Form

New Hampshire | LIVE FREE AND LEARN  
Department of Education

[Home](#) [Education Pathways](#) [Parents and Students](#) [Educators](#) [Partners](#) [Who We Are](#) [Data Reports](#) [Right To Know](#) [Contact Us](#)

[Home](#) [Who We Are](#) [Division of Career Support](#) [Bureau of Student Wellness and Nutrition](#) [National School Lunch Program](#)

### National School Lunch Program

The purpose of the National School Lunch Program is to safeguard the health and well-being of the Nation's children, as declared in 1946 by Congress in the National School Lunch Act. The School Lunch Program makes it possible for schools to serve nutritious inexpensive lunches to students each day. Schools may also serve meals during summer months. Last school year, in NH, over 30 million meals were reimbursed. USDA provides program funding and administration.

### Special Dietary Medical Statement Form

- [Special Dietary Medical State Form](#)

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**MUST BE PLACED ON YOUR ORGANIZATION LETTERHEAD**

**SPECIAL DIETARY MEDICAL STATEMENT**  
Please send to Student's School/Institution as listed above

Student Full Name: \_\_\_\_\_ Date Completed: \_\_\_\_\_

School and Grade: \_\_\_\_\_

**MEAL MODIFICATIONS MADE OUTSIDE THE MEAL PATTERN**  
(Accommodation that alters the USDA meal pattern, ex. fruit served to be served to student)  
Foods to be Avoided: \_\_\_\_\_  
Brief explanation of how exposure to this food affects the student: \_\_\_\_\_  
Recommended Substitute to this Food: \_\_\_\_\_  
Signature of Licensed Medical Professional: \_\_\_\_\_ Printed Name of Licensed Medical Professional: \_\_\_\_\_

**MEAL MODIFICATIONS MADE WITHIN THE MEAL PATTERN**  
(Accommodation within one of the 5 food items, ex. orange served instead of an apple)  
Foods to be Avoided: \_\_\_\_\_  
Brief explanation of how exposure to this food affects the student: \_\_\_\_\_  
Recommended Substitute to this Food: \_\_\_\_\_  
Signature: \_\_\_\_\_ Printed Name: \_\_\_\_\_ Title: \_\_\_\_\_

Please refer to Page 14 of 14 (USDA) for ACCOMMODATING CHILDREN WITH DISABILITIES IN THE SCHOOL MEAL PROGRAM, JULY 25, 2017  
Meal Pattern = Usual Meal Alternate, Grain, Vegetable, Fruit and Milk  
TSP Assume Role for the  
EQUAL OPPORTUNITY (EEO) OFFICE: EQUAL EDUCATIONAL OPPORTUNITIES  
This institution is an equal opportunity provider. Updated 12/20/22

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**Limitations of the Special Meals Form**

Provides limited guidance to those preparing the food and those feeding the child

Does not explain the "why?" or indicate the modifications needed for: how a child is fed; feeding equipment; positioning; special feeding equipment or other precautions needed to keep the child safe during meals/snacks

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**Work Arounds**

- Create a safe eating and drinking plan that incorporates what the child needs
- Reference it on the State form
- Have the physician sign both

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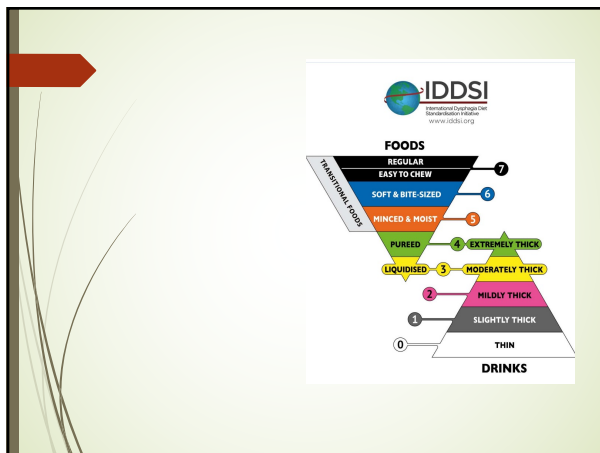
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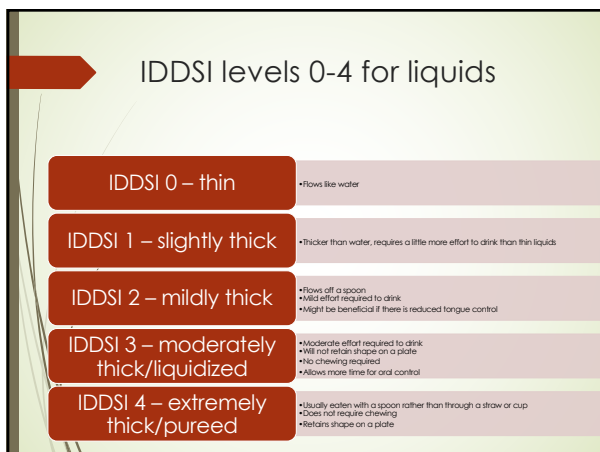
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## Thickened Liquids

Why - Thickened liquids flow more slowly than thin liquids, and this provides extra time for a person with dysphagia to achieve airway protection during swallowing.

How - commercial thickeners (Simply Thick, Purathick, ThickIt), using foods, naturally thick liquids, a combination

Assessing the consistency - flow test or funnel test

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## Pearls to Increase Acceptance of Thickened Liquids

- Ice cold
- Thickened ice cubes
- Fruit infused water
- Natural non-caloric sweeteners
- Use of natural thickeners

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## Assuring Adequate Hydration

- Work with dietitian to establish hydration needs
- Try a hydration schedule with timed offering
- Have fluid measures marked on the side of the beverage container

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### Pearls for Reimbursement of Thickener

- Letter of Medical Necessity
- Dysphagia Outreach Project
- Oley Foundation

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### Texture Modification

- Why – modifying the texture of foods supports a match with skill, safety, efficiency, nutrition needs, weight, age level, and GI needs.
- How – food processor, high speed blender, food chopper, pre-packaged foods
- Assessing the consistency of foods – fork drip test, spoon tilt test, chopstick test, fork pressure test, finger test

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### IDDSI 3-7 foods

<b>IDDSI 3 – moderately thick/liquified</b> <ul style="list-style-type: none"> <li>• Smooth, no chewing required</li> <li>• Does not retain shape on a plate</li> <li>• Eaten with a spoon</li> </ul>	<b>IDDSI 4 – extremely thick/pureed</b> <ul style="list-style-type: none"> <li>• Does not require chewing</li> <li>• Retains shape on a plate</li> <li>• Not sticky</li> <li>• Can be eaten with a fork but usually with a spoon</li> </ul>	<b>IDDSI 5 – minced and moist</b> <ul style="list-style-type: none"> <li>• Can be eaten with a fork or spoon</li> <li>• No separate thin liquid</li> <li>• Small lumps visible within the food</li> </ul>	<b>IDDSI 6 – soft and bite-sized</b> <ul style="list-style-type: none"> <li>• Can be eaten with a fork or spoon</li> <li>• Can be mashed with pressure from a utensil</li> <li>• Chewing is required prior to swallowing</li> </ul>	<b>IDDSI 7 – easy to chew</b> <ul style="list-style-type: none"> <li>• Normal, everyday food of soft and tender texture that are developmentally and age appropriate</li> </ul>
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## Pearls for Teaching IDDSI to Caregivers

This includes – paraprofessionals, parents, teachers, therapist, and food service staff

- Testing Handouts from IDDSI.com
- Placements for size of bites
- Videos on youtube from IDDSI
- IDDSI App

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## Training of the Safe Eating Plan

- Family
  - Family stressors
  - Family dynamics
  - Family dynamics
- School
  - Therapy Team
  - Teachers and Paras
  - Nurse
  - Food Service
- Children in Residential Placement

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## How often is the Safe Eating Plan and SMPF revisited?

At least once a year  
If changes occur in the student's skill  
If new information is gathered from updated instrumental assessment of swallow safety  
As needed

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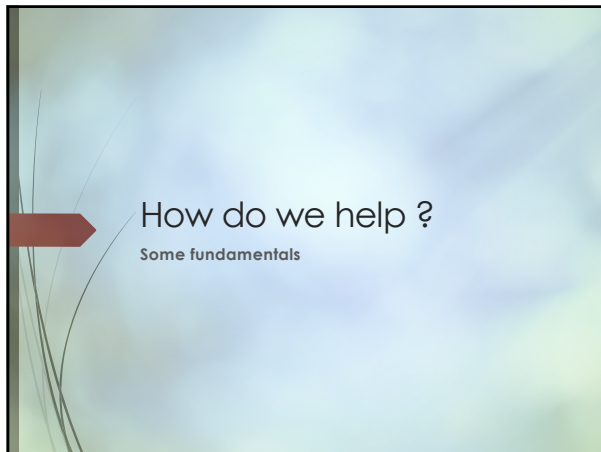
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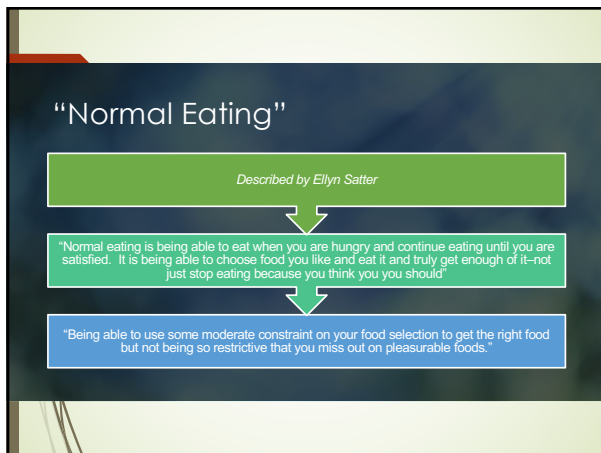
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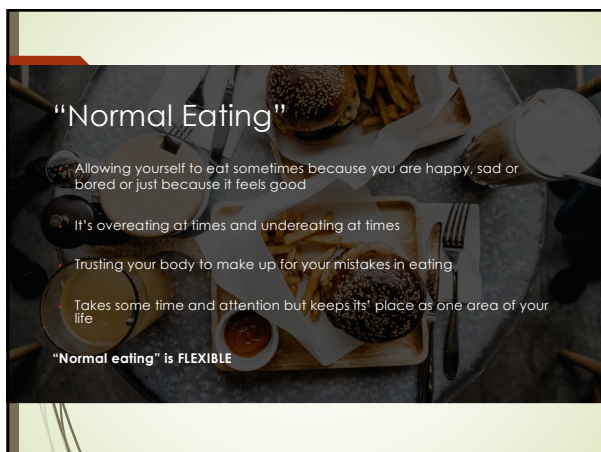
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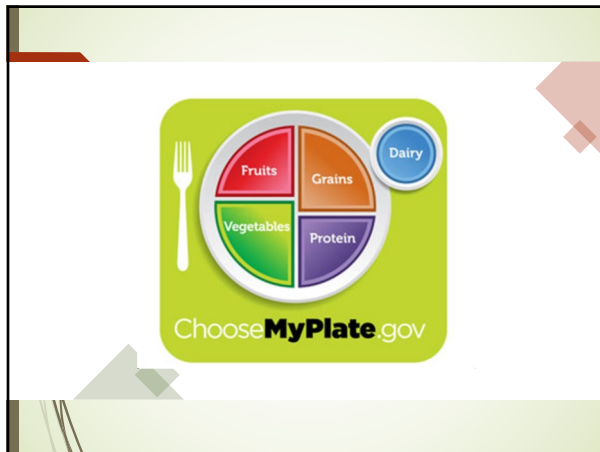
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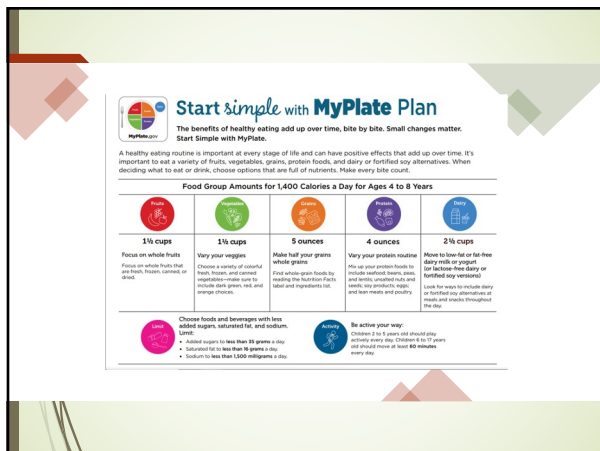
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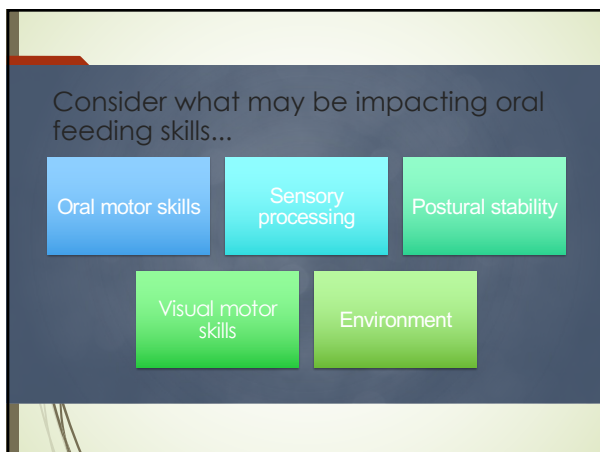
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Supporting Oral Motor skills for Chewing

- Is the oral motor program developing new skills or maintaining skills?
- If using tools, be sure they look age appropriate!
- Does the texture of the food match oral motor skills, or is texture modification needed?

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Sensory Integration: the ability to take in information from all of the senses, process that information, and the produce an adaptive response. Jean Ayers

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Sensory processing considerations for eating and drinking

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**Ideas to support a student with sensory processing differences**

- Be mindful of fatigue, hunger, pain, thirst, illness
- Systematic desensitization
- Food chaining
- Be a food scientist – SOS Approach to Feeding

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## Feeding Strategies/Routines

**Good advice for ALL children**

*Caregiver*

- provides a quiet, pleasant, distraction-free and safe environment for meals and snacks
- Do not bribe or force a child to clean the plate
- Seat the child at the table for meals and snacks
- Discourage walking or playing while eating
- Be sure child is properly positioned—feet on the floor and table at stomach level.
- Serve the child most of the foods the family is eating. Avoid being a short order cook
- Model healthful eating habits and manners.

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## Establishing Mealtime Routines

**Good advice for ALL children**

- Involve child in menu planning, food shopping, coupon clipping and food preparation, ie. setting table, putting groceries away, loading dishwasher, breaking eggs
- Encourage child to try at least 1 bite of a new food. It takes several introductions of a food before a child will pick it up and try int. Avoid tricking, bribing or forcing the child to try
- Present desserts and sweets as the last course of the meal. Do not use as reward for finishing the meal. This teaches that dessert is the best part of the meal and increases preference for sweets or may reduce acceptance of non-sweetened foods.
- Allow preschoolers who have finished eating to leave the table
- Allow child to choose how much is eaten from 2-3 choices

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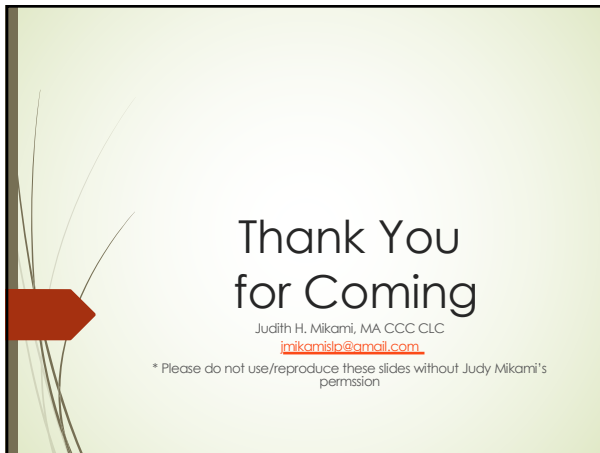
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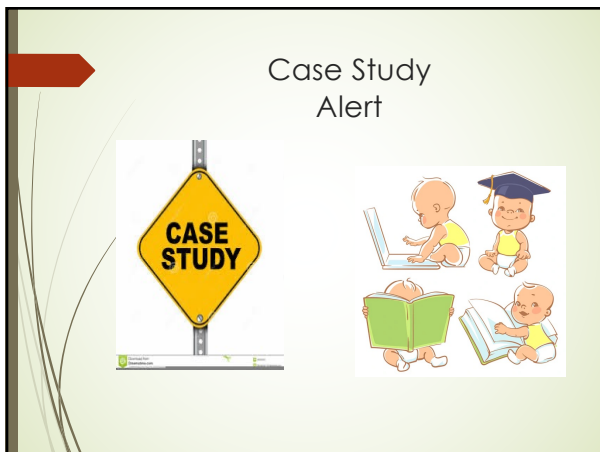
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