

## Asking the Right Questions is Key



Erin Sundseth Ross, Ph.D., CCC-SLP



1

## Education

- Ph.D., University of Colorado Health Sciences Center, Clinical Sciences, Health Services Research (2007)
- Post-Doctoral Fellowship in the Section of Nutrition, Department of Pediatrics, School of Medicine, University of Colorado Denver (2007-2009)
- Master of Arts, California State University Stanislaus, Speech and Language Pathology (1988)

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2

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**Erin Ross**

**Gerber Foods** : Consultant  
**Intertek**: Consultant  
**Toomey & Associates**: Speaker  
**Feeding FUNDamentals**: Receive a salary

These financial relationships with ineligible companies have been mitigated by PeerPoint Medical Education Institute and Feeding Matters.

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Financial: Consultant for Gerber Foods and for Intertek; speaker for Toomey & Associates, and I receive a salary from Feeding FUNDamentals, LLC. My presentation will not be used to sell a product or service.

Nonfinancial: Chair of the Advocacy Committee with Feeding Matters

3

## Current Positions

- Assistant Clinical Professor, University of Colorado Denver, School of Medicine, Department of Pediatrics
- Faculty, Rocky Mountain University of Health Professions
- Developmental Specialist, HealthONE Hospital System, Denver, Colorado
- President, Feeding Fundamentals, LLC

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4

## Learner Outcomes

<b>State</b>	the 4 domains of PFD
<b>List</b>	two tools designed to help with asking the right questions to facilitate early identification of PFD
<b>List</b>	at least one question from each of the 4 domains of PFD that may help identify PFD

Learner Outcomes

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5

## What do you think of when you think of eating?

- Home
- Eating Out
- Fun
- Laughter
- Comfort
- Celebrations
- Hunger and/or Fullness
- Connections with friends and family

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## Do you think about...

- Am I eating enough to grow?
- Have I eaten a prescribed amount of calories?
- Am I staying at the table long enough?
- Did I cough or choke that time?
- Did I gag on any textures or because I did not chew well?
- Am I eating what other people are telling me to eat?
- Have I gotten all of my vitamins and minerals?

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7

7

## Feeding is the EXPERIENCE!

- Eating is necessary to obtain adequate nutrition, AND...
- Eating needs to be safe and comfortable from a physical standpoint, AND...
- Feeding is a social experience
- Parents don't just want their child to grow...
- We want our mealtimes to be happy times, and our child to eat "like every one else"

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8

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## Parenting stressors

- Parents often feel anxious and isolated
- Parents are typically the first to raise a concern
- Parents spend most of their day
  - Thinking about feedings
  - Preparing feedings
  - Cleaning up feedings
  - Giving feedings

Estrem et al., 2018

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## Parenting stressors

- Parents spend time trying to get medical professionals to
  - Listen to them
  - Find a diagnosis
- They may not have anyone (even medical/therapy team)
  - Talk to them about the problem
  - Let them talk about the stressors

Estrem et al., 2018

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## Parents feel helpless and disempowered

- Deconstruction (loss and disempowerment)
  - Losing the dream
  - Living life on the margins
  - Moving from mother to onlooker
- Reconstruction (Getting Through)
  - Letting go (dream) to valuing (real)
  - Becoming the enabler and facilitator
  - Negotiating balance

Hewetson et al. 2009

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11

## What do you think of professionally?

- Do you consider why the child has a feeding problem?
- Do you consider the child may have more than one issue?
- How do you interpret the child's behaviors?
- Do you ask parents what they think might be going on?
- Do you ask parents why they are using the strategies that they are using?
- Do you ask parents what would be their ideal mealtime?
- Do you think about what you do NOT know?

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12

12

“(Parents) need those of us providing healthcare to listen to their expertise and partner with them as the complexity of the problem is explored”

Thoyre, 2018

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13

Eating does not just “happen”

- The ability to eat relies on closely related and complementary domains
  - Medical
  - Nutrition
  - Feeding Skill
  - Psychosocial

Goday et al. 2019

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14

14

Eating is a complex interplay of domains

- Eating is a developmental skill as well as a physical task
- The complexity of feeding problems may be missed with one perspective
- Assessment and treatment feeding disorders needs to include multi-disciplinary perspectives

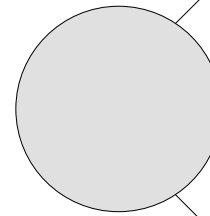
Goday et al. 2019; Borowitz & Borowitz 2018; Jung et al. 2016; Ross 2016

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15

15

PFD



Impaired oral intake that is not age-appropriate, lasting at least 2 weeks, and is associated with one or more of the following:

- Medical
- Nutritional
- Feeding skill
- Psychosocial dysfunction

Learner Outcome #1

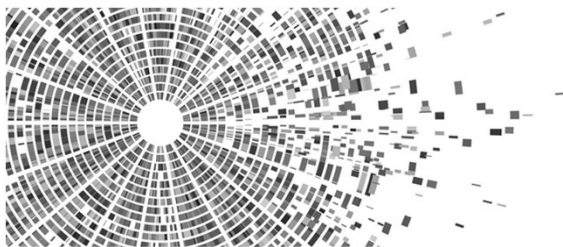
Goday et al., 2019

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16

Prevalence



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Recent prevalence estimates of PFD

- Analysis of number of children who meet criteria for diagnosis of PFD (year 2014)
- Annual prevalence of PFD:
  - 1 in 23 children under 5 years in Wisconsin (public)
  - 1 in 24 children under 5 years in Arizona (public)
  - 1 in 37 in children under 5 years (private)

Kovacic et al. 2021

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18

## Chronic comorbidities and PFD

- Respiratory (65-80%)
- Gastrointestinal (55-75%)
- Premature/Neonate (35-55%)
- Technology dependency (50-70%)
- Transplantation (30-45%)

Kovacic et al. 2021  
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19

19

## Prematurity and PFD

- A meta-analysis shows 42% of premature infants struggle with eating after discharge<sup>1</sup>
- Infants born prematurely score significantly different from term peers on feeding measures of problematic feeding behaviors<sup>1, 2, 3</sup>

Pados et al. 2021; Jung et al. 2016; Park et al. 2019

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20

20

## Sensory sensitivities and PFD

- Significant correlations among picky eating, poor weight gain, and sensory sensitivities
  - Sensory sensitivities are correlated with NOT outgrowing picky eating behaviors in a longitudinal study (4 years to 6 years)<sup>1</sup>
  - 68%-100% of children seen in a multidisciplinary feeding assessment scored atypical on sensory assessments<sup>2, 3, 5</sup>
  - Atypical sensory scoring also correlates with several medical comorbidities<sup>3,4,6</sup>

Steinsbekk et al. 2017; Yi et al. 2015; Davis et al. 2013; Jung et al. 2016; Kim et al. 2021; Nadon et al. 2011

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21

21

## Feeding is the first developmental skill

- Children who go on to be diagnosed with motor, language, and/or behavior problems often show problems in feeding first<sup>1</sup>
- Children with ASD have more referrals for feeding, sleeping & crying problems as infants<sup>2,3</sup>
- Children who go on to be diagnosed with motor disorders have a higher risk of having early feeding problems<sup>4</sup>

Motion et al. 2001; Emond et al. 2010; Olsson et al. 2013; Zwicker et al. 2020

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23

## How we may contribute to the problem...

- Physicians may look at growth as the single measure of feedings...
  - If the child is growing, they must be eating enough
  - We may not listen to the parent's story
- If families are struggling, and growth becomes the measure of success
  - Families may begin to do extraordinary things to get their child to eat and grow

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24

24

## How we may contribute to the problem...

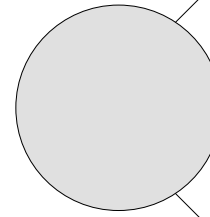
- Therapists then see the family doing things that are not helpful, and make assumptions about what is causing the problem...
- Dietitians may see what the child is eating and make assumptions about the parent's knowledge of nutrition, or parenting abilities

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25

25

## PFD



Impaired oral intake that is not age-appropriate, lasting at least 2 weeks, and is associated with one or more of the following:

- Medical
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- Psychosocial dysfunction

Learner Outcome #1

Goday et al., 2019

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26

26

## Medical dysfunction

As characterized by:

- Cardiorespiratory compromise during oral feeding
- Aspiration or recurrent aspiration pneumonitis

Goday et al. 2019

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## Nutrition dysfunction

As characterized by:

- Malnutrition
- Specific nutrient deficiency or significantly restricted intake of one or more nutrients resulting from decreased dietary diversity
- Reliance on enteral feeds or oral supplements to sustain nutrition and/or hydration

Goday et al. 2019

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## Feeding skill dysfunction

As characterized by:

- Need for texture modification of liquid or food
- Use of modified feeding position or equipment
- Use of modified feeding strategies

Goday et al. 2019

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## Psychosocial dysfunction

As characterized by:

- Active or passive avoidance behaviors by child when eating or being fed
- Inappropriate caregiver management of child's feeding and/or nutrition needs
- Disruption of social functioning within a feeding context
- Disruption of caregiver-child relationship associated with feeding

Goday et al. 2019

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30

30

### But which comes first?

- The more worried a mother is about her child's feeding and or weight, the more mealtime interactions are impacted<sup>1</sup>
- With infants<sup>2</sup>
  - Less support of suck/swallow/breathe
  - More stimulation
- With children<sup>1</sup>
  - More intrusive
  - Less structured
- \*Fussy eating in 1.5-3 y predicted more pressure to eat by parents at 4 y, which predicted increased fussing at 6 y<sup>3</sup>

Gueron-Sela et al. 2011; Park et al. 2016; Jansen et al. 2017  
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### Different children...different strategies...

- In studies of parents with at least two children
- Often use different strategies with different children, based in part on picky behaviors and on weight
- For children who are picky or with poor weight gain, parents use more
  - Pressure to eat
  - "Short-order cooking"

Berge et al. 2016; Farrow et al. 2009  
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### The problem with seeing through one lens...

- Consider that a child may have a problem in an associated area and if you don't know to ask
  - Miss important factors that may be causing the problem
  - Waste the family's time and money
  - May actually do harm to the child
- No one person is an expert at everything...
- By partnering with the family and the pediatrician first, even single providers can build a virtual team

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### Tools to help with knowing what questions to ask...

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**AUTHORS**

Joan C. Arvedson, PhD, CCC-SLP, BC-NCD, BRS-S, ASHA Fellow  
 Joy V. Browne, PhD, PCNS-BC, IMH(E)  
 Amy L. Delaney, PhD, CCC-SLP  
 Mary Beth Feuling, MS, RD, CNSD  
 Elizabeth Fischer, PhD  
 Erika Gisel, PhD, OTR, etc.  
 Marsha Dunn-Klein, Med, OTR/L  
 Suzanna Evans Morris, PhD  
 Erin Sundseth Ross, PhD, CCC-SLP  
 Colin Rudolph, MD, PhD  
 Kay A. Toomey, PhD

**EDITS**

Aimee Langlois  
 Professor Emerita, Humboldt State University  
 Trudi Normal-Murch  
 PhD, CCC-SLP  
 Daniel B. Kessler  
 MD

**INFANT & CHILD FEEDING QUESTIONNAIRE**  
*"Maturation and other associated medical concerns are preventable with early detection & intervention"*

- **GOAL:** Improve PCP early identification and referral of children at risk for pediatric feeding disorders and appropriate intervention
- **RED FLAGS:** The questionnaire identifies red flags for feeding concerns
- **PRELIMINARY FINDINGS:** 97% Sensitivity & Specificity\* with 4 questions for identifying a pediatric feeding disorder.

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35

www.feedingmatters.org/questionnaire

Child's Birthdate  
 Feb 2 2022

How many gestational weeks?  
 Full Term

Does your baby usually like to be fed? \*

No  
 Yes

Does your baby feed more often than every two hours? \*

No  
 Yes

Learner Outcome #2

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36

## Infant and Child Feeding Questionnaire

- Designed to help parents & professionals with early identification
  - Online questionnaire for child feeding behaviors from birth to 3 years of age
  - Anticipatory guidance for each question
  - Identifies areas of potential concern for further investigation
  - Six questions differentiated children with feeding problems from typically developing children
  - These six questions are now part of a screener, available from Feeding Matters

Learner Outcome #2

Barkmeier-Kraemer et al. 2017; Silverman et al. 2020

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37

## PFD ICD-10 TOOLKIT

PFD education, identification, and advocacy tools for professionals and families

The PFD ICD-10 Toolkit is a collection of free resources designed to promote awareness, identification, and comprehensive assessment and management of PFD. The Toolkit can be downloaded in its entirety or as individual resources. The Toolkit will be periodically updated and expanded as additional resource needs are identified. Please share your feedback as we work together to make PFD a household name.

Learner Outcome #2

<https://www.feedingmatters.org/toolkit/>

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38

<https://www.feedingmatters.org/toolkit/>

## Feeding Matters resource

### PFD Toolkit

- Signs and Symptoms of PFD by Domains
- Provides a guideline within each domain, with questions to explore with families
- Questions lead to getting answers...
- If you don't ask the question, you may miss important information

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39

## Sample questions for medical domain

- Labored breathing? Color changes in lips/face during mealtimes?
- Coughing, choking, gagging or retching during mealtimes?
- Hard swallows, gurgle/squeak sounds, sweating during mealtimes?
- Recurring upper respiratory infections?
- Concerns with gastrointestinal system (vomiting, food sensitivities)?
- Poor hunger drive?
- Physical discomfort during mealtimes?

Learner Outcome #3

<https://www.feedingmatters.org/toolkit/>

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## Sample questions for nutritional domain

- Eating enough to grow, drinking enough to hydrate?
- Rapid changes in weight/height?
- Lack of specific micronutrients/need for supplements?
- Need for supplemental tube feedings?
- Constipation?
- Limited dietary diversity?
- Reliance on a specific food/liquid for nutrition?

Learner Outcome #3

<https://www.feedingmatters.org/toolkit/>

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41

## Sample questions for feeding skills domain

- Unable to eat/drink enough to grow well?
- Very short or very long mealtimes?
- Need for diet modifications?
- Need for special strategies, positioning, equipment?

Learner Outcome #3

<https://www.feedingmatters.org/toolkit/>

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### Sample questions for feeding skills domain

- Needs help to latch?
- Has a weak suck?
- Often too tired to eat, quickly falls asleep when eating?
- Eats best when asleep (dream feeds)?
- Unable to transition?

Learner Outcome #3

<https://www.feedingmatters.org/toolkit/>

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### Sample questions for feeding skills domain

- Grazing all day?
- Refuses to eat or drink specific textures or entire nutrition groups?
- Needs distractions to eat?
- Eats only when given praise, bribes, threats?
- Difficulty chewing age-appropriate foods?
- Unable to eat in unfamiliar/new settings?

Learner Outcome #3

<https://www.feedingmatters.org/toolkit/>

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### Sample questions for psychosocial domain

- Refuses to come to table, or eat with family/others?
- Refuses to eat what is offered or eat at all?
- Disruptive mealtime behaviors?
- Parent is stressed/worried or afraid when feeding child?
- Use of distractions/rewards/bribes/threats during mealtimes?
- Unpleasant mealtime interactions?

Learner Outcome #3

<https://www.feedingmatters.org/toolkit/>

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### Additional questions that matter...

- Does your baby/child usually like to be fed?
- Does your baby/child let you know when they are hungry?
- Do you think your baby/child eats enough?
- Do you enjoy feeding time with your baby/child?
- Are you worried about your child's feeding?
- What is your day like with this child?
- What would you like help with?

Learner Outcome #2

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46

## Case Studies....

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47

47

### Case study - Mira

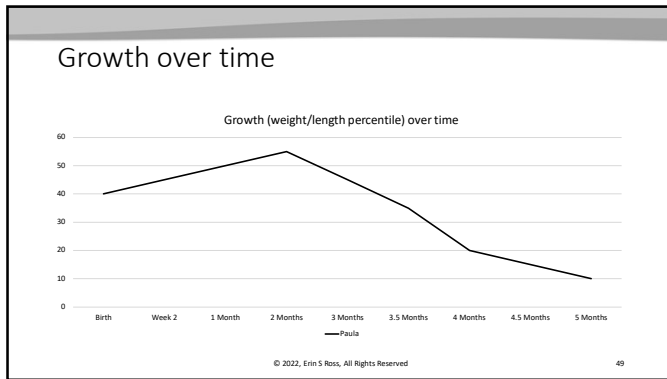
- Mira comes to you to help her transition off her supplemental tube feedings
- She is 5 months of age
- Her mother has been told to use an oral-motor program to get her to strengthen her sucking skills and to desensitize her mouth

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48

48





49

### What did you notice?

- She was born at an average size for age
  - 40<sup>th</sup> percentile in weight-for-length
- Mira grew well between birth and 2 months of age
  - 55<sup>th</sup> percentile in weight-for-length
- Beginning at 3 months of age, Mira's weight-for-length percentiles began to drop
- What questions do you need to ask?

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### Case study - Mira

- Mira started out exclusively breastfeeding
  - She also ate well with bottles
- At two months her growth was good, but she was a fussy eater
- At three months she was seen for an ear infection
  - Growth at that time was starting to fall off her curve
  - Mira was increasingly fussy but did not vomit

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### Case study - Mira

- Physician told mom to start introducing formula in a bottle
- Mira's follow up at 4 months was worse still and she was increasingly fussy
- Mira wanted to breastfeed "all the time"
- Mira's parents said she really fought the bottle feedings

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### Case study - Mira

- Physician told parents to give more bottles and limit breastfeeding
- Mira's physician referred for a tongue-tie procedure (frenotomy) to improve volumes
- Mira's parents report lots of crying and aversions with surgery aftercare
- Feedings got worse

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### Case Study - Mira

- At 4.5 months growth still faltering
- Physician recommended use of a supplemental tube
- Mira stopped eating
- Mira was hospitalized and a VFSS was ordered
- VFSS was unremarkable
- Other than ear infections, Mira has been healthy

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54

Let's take a minute....

- What questions do you have?
- Have you thought of what you have not considered?
- Are you thinking across domains?
- Who would you call in?
- Did you consider looking at the questions across all of the four domains?

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By bringing in other disciplines....

- Mira was referred to GI
- Mira was diagnosed with a cow's milk protein allergy
- Mira was changed to a dairy-free elemental formula

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"We fixed her mouth. But there was nothing wrong with her mouth. It was her stomach... "

*Mother's quote*

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Case study: Morgan

- Morgan was born at 27 weeks PMA
- She had an uneventful course in the NICU
- Morgan was seen in developmental follow-up clinic until she was two years of age
  - Morgan has met all required milestones
  - She has been discharged from all therapy
- At three years of age, Morgan is referred to you as a private practitioner in Occupational Therapy because she "just won't eat"

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Case study: Morgan

- You watch Morgan play in the gym, and she is slightly lower normal muscle tone and a bit unsteady but otherwise doing just fine with all tasks you have given her
- Morgan happily plays in a variety of texture bins
- She swings on the suspended equipment and hops on the trampoline
- She talks a lot – and seems very bright
- She seems very healthy – other than she is small and skinny

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Case study: Morgan

- When you sit with her mother and Morgan for a picnic:
  - Morgan begins to squirm and try to get out of her chair
  - Mom gives her some Cheetos and Morgan sits back down
  - When mom tries to give her some fruit and cheese, she shows obvious distress and keeps saying "I'm not hungry"
  - Mother then brings out some baby food pouches and hands one to Morgan

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### Case study: Morgan

- Mother pulls out a computer tablet and says “she won’t ever eat unless she watches her favorite show on this”
- When mother starts the video, Morgan seems to go into a “trance”, sucking on the baby food pouch
- When you hand Morgan a piece of bread, she takes it and puts it in her mouth without looking at it
  - She immediately gags and takes it out with her hand
- Morgan says she’s all done and gets out of her chair

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61

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### Let’s take a minute....

- What questions do you have?
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### Multidisciplinary Team Assessment....

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Nutrition finds Morgan has several nutrient deficiencies, including iron and zinc, and low calorie intake

- She has low energy, low endurance, low appetite

Medical finds Morgan has a carnitine deficiency

- She has a muscle disorder that affects her muscle tone and thereby her energy to eat

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### The rest of the story

- Speech Pathology finds
  - Poor tracking of foods
  - No tongue lateralization
  - Weak oral musculature
  - Chewing too far forward in the mouth

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### The rest of the story

- Psychology talks with mother about the use of the tablet
  - Mom recalls she started using it when Morgan was about a year old
  - Mother started using it to distract Morgan from fighting – “she will at least stay at the table”
  - Mom has been giving Morgan easy to eat “junk” foods and baby food pouches “because she will eat when she is not paying attention”

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66

66

### Case Study: Jennie

- You are teaching at a local conference, and a speech pathologist comes up to you and shows you a video of an infant on her case load
- The baby's mother is also with the therapist
- The baby was born prematurely (30 weeks) and is now 3 months old corrected
- The speech pathologist states that they have been doing oral work with the baby, but she is not eating more and may get a nasal-gastric tube soon

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67

### Your initial thoughts

- After watching the baby eat, you notice she is drooling a lot and she is gulping frantically
- You point out that she is breathing erratically, with long pauses in her breathing so she can try and keep up with the flow rate
- Your first impression.... She is struggling with the flow rate and needs help from the therapist to coordinate her suck/swallow and breathing sequences

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68

68

### But then....

- The mother comments that her baby vomits "all the time"
- You start to wonder....
- You ask about what "all the time" means
- Mom says she has been keeping a log of what the baby eats, and what she vomits

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69

### So....

- You ask to see the log
- You notice the infant appears to be vomiting at least half of what she is eating, every day
- What might be your next move?

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70

70

### Let's take a minute....

- What questions do you have?
- Have you thought of what you have not considered?
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- Who would you call in?
- Did you consider looking at the questions across all of the four domains?

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71

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### Refer to a multidisciplinary team

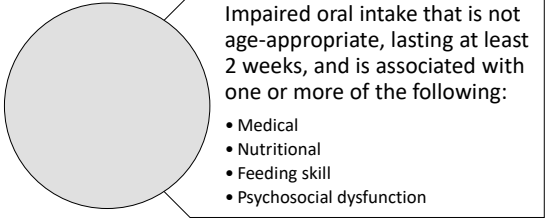
- First, you are not the treating therapist
- This therapist and this mother clearly need support from a team
- What do you think is/are her problem(s)
  - Medical
  - Nutrition
  - Feeding Skill
  - Psychosocial

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72

72

**PFD**



Impaired oral intake that is not age-appropriate, lasting at least 2 weeks, and is associated with one or more of the following:

- Medical
- Nutritional
- Feeding skill
- Psychosocial dysfunction

Learner Outcome #1

Goday et al., 2019

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73

...”Successful management of PFDs is only possible with the care and expertise of a multidisciplinary team, which includes parents/caregivers”

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74

Assessment leads to treatment

- If children have multiple interactive problems that lead to their feeding problems....
- Interventions should also be addressing the multiple factors that have created the feeding problem
  - Medical
  - Feeding Skills – Oral, Motor, Cognitive, Developmental
  - Sensory
  - Nutrition
  - Psychosocial

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If PFD includes “ disturbance in oral intake of nutrients, inappropriate for age”

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Medical domain

- Evidenced by any of the following
  - Cardiorespiratory compromise during oral feeding
  - Aspiration or recurrent aspiration pneumonitis
- Then the primary physician at a minimum, and specialists as needed, are necessary to monitor the health and development of the infant/child

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77

Nutrition domain

- Evidenced by any of the following
  - Malnutrition
  - Specific nutrient deficiency or significantly restricted intake of one or more nutrients resulting from decreased dietary diversity
  - Reliance on enteral feeds or oral supplements to sustain nutrition and/or hydration

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78

## Nutrition domain

- Then treatment should consider the nutrition of the infant/child and verify that the child is
  - Well nourished, AND
  - Receiving appropriate nutrients through dietary diversity
  - No longer relying on enteral feeds or oral supplements

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79

79

## Feeding skill domain

- And within feeding skill domain includes
  - Need for texture modification of liquid or food
  - Use of modified feeding position or equipment
  - Use of modified feeding strategies

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## Feeding skill domain

- Then treatment should address the feeding skill deficits to return the child to eating without the need to modify
  - Texture of food or liquid
  - Feeding position
  - Feeding equipment
  - Feeding strategies

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## Psychosocial domain

- And within the psychosocial domain, includes
  - Active or passive avoidance behaviors by child when feeding or being fed
  - Inappropriate caregiver management of child's feeding and/or nutrition needs
  - Disruption of social functioning within a feeding context
  - Disruption of caregiver-child relationship associated with feeding

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82

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## Psychosocial Domain

Then treatment should consider mealtime interactions

- With active participation by child
- With caregivers who can feed their child without special techniques
- With typical social interactions
- That exemplify connected, supportive caregiver-child relationships

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83

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## Mealtimes

- Eating is not just for growth
- Eating is not just for health
- Eating is a JOY!
- Parents and their children with PFD deserve to enjoy the same love of food....
- Pleasurable feedings matter!

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84

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“...Infant feeding is a matter of infant-mother relationship, a putting into practice of a love relationship between two human beings.”

Winnicott, 1987

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“A baby’s ability to eat and a mother’s ability to feed her baby are at the heart of who she is as a mother.”

Thomas, 1995

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**A majority of the time together in the first year is spent feeding**

Thomas, 1995

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For babies.... Let’s move conceptually....

<p><b>“Feeding”</b></p> <ul style="list-style-type: none"> <li>• To give food</li> <li>• To supply with nourishment</li> </ul>	<p><b>“Nourishing”</b></p> <ul style="list-style-type: none"> <li>• To foster development</li> <li>• To support and encourage, as during the period of training or development</li> </ul>
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88

For children with PFD

“Changing Behaviors”

“Pleasurable meals with friends and family, eating in an age-appropriate way”

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One more resource..... Feeding Matters!

**PFD ALLIANCE**

Stay informed and access resources; membership is free.

Join now and access member portal

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Remember...YOU will probably be the first....

- Feeding problems are frequently the first developmental issue
- The underlying developmental problems are often diagnosed after the feeding problem is identified
  - Sensory problems
  - Oral-motor problems
  - Motor problems
  - Language problems
  - Autism Spectrum Disorders

Motion et al. 2001; Emond et al. 2010; Olsson et al. 2013; Zwicker et al. 2022; Sharp et al. 2010; Steinsbekk et al. 2016  
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**Don't Go It Alone....**

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92

92

**“Simplistic Interventions  
Applied to Complex  
Problems Risk Unintended  
Consequences”**

Douglas, 2013

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Work Together as a Team....

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To Ask

The Right Questions

Because.....

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Asking the Right Questions Is Key!

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96

96





97



98