

Meeting Halfway: A Multidisciplinary Approach to PFD Treatment in Children With Autism

JESSICA OWENS CPNP-PC, MSN
SHARON WALLACE RD, CSP, LDN
EMILY BRAGG MS, CCC-SLP

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Disclosures

- ▶ Jessica Owens- No disclosures
- ▶ Emily Bragg- No disclosures
- ▶ Sharon Wallace- International Pediatric Feeding Disorders Conference (IPFDC) Planning Committee Member

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UNC Feeding Team Who are we?

Chapel Hill

- GI Pediatric Nurse Practitioner
- Registered Dietitian
- Speech-Language Pathologist (Feeding focused)

Raleigh

- GI Pediatric Nurse Practitioner
- Registered Dietitian
- Speech-Language Pathologist (Feeding focused)

Virtual

- GI Pediatric Nurse Practitioner
- Registered Dietitian

EVALUATE AND TREAT PATIENTS FROM BIRTH UNTIL 21ST BIRTHDAY

RANGE OF MEDICAL AND FEEDING COMPLEXITIES

COMPREHENSIVE VISIT WITH ALL TEAM MEMBERS FOR THE PATIENT AND CAREGIVER

WORK CLOSELY UNDER THE PEDIATRIC FEEDING DISORDER FRAMEWORK

We receive nearly 1000 referrals per year to our clinic and see an average of 60 patients per week between our 3 teams

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Children with ASD are at a greater risk of experiencing GI tract symptoms vs those without ASD

- ▶ Timely and accurate diagnoses of GI disorders can be challenging due to patient's expressive communication ability and style as well as potential for difference in pain perception
- ▶ Feeding difficulty symptoms including gagging, retching, vomiting and food refusal or selectivity often found in children with ASD may have underlying GI etiology that overlap.
- ▶ Current literature suggests an increased likelihood of GI disorders in children with higher levels of autism- relationship continues to be studied.

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Common GI symptoms and diagnoses found in children with autism

- ▶ **Constipation or difficulty passing stools**
- ▶ **Eosinophilic Esophagitis**
- ▶ **GERD/GER**
- ▶ **Dysphagia**
- ▶ Food intolerances/allergies
- ▶ Gluten sensitivities/ celiac disease
- ▶ Gastritis/esophagitis
- ▶ Visceral hypersensitivity
- ▶ **Food refusal**
- ▶ Unintentional weight loss
- ▶ Poor appetite
- ▶ Bloating
- ▶ Generalized abdominal pain
- ▶ Diarrhea

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Diagnostic Methods

- ▶ Comprehensive history and physical including family history
- ▶ Diet eliminations (gluten, dairy)
- ▶ GI endoscopy
- ▶ Other X-ray studies including abdominal x-rays, upper GI studies, gastric emptying scans and MBSS (modified barium swallow study)
- ▶ pH impedance probe studies
- ▶ Empiric medication trials
- ▶ Laboratory studies (blood, fecal most common)

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Frequently Used Treatments

<p style="text-align: center; margin: 0;">GERD</p> <ol style="list-style-type: none"> 1. H2 antagonist 2. PPI (proton pump inhibitor) 3. Pro-kinetic/motility 4. Diet modification 	<p style="text-align: center; margin: 0;">Constipation</p> <ol style="list-style-type: none"> 1. Osmotic Laxatives 2. Stimulant Laxatives 3. Diet modification
<p style="text-align: center; margin: 0;">Eosinophilic Esophagitis</p> <ol style="list-style-type: none"> 1. High dose PPI 2. Oral viscous budesonide 3. Dupilumab 4. Diet elimination 	<p style="text-align: center; margin: 0;">Other medications</p> <ol style="list-style-type: none"> 1. Appetite stimulants 2. Neuromodulators

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Case study Lilly: 3-year-old diagnosed with ASD

History of Present Illness

- ▶ Birth history includes born 36 weeks with no complications
- ▶ Breast and formula fed, poor tolerance of standard formulas, had best tolerance with an extensively hydrolyzed formula.
- ▶ History of infantile GERD that resolved with time and short-term acid suppression therapy.
- ▶ No concerns with feeding until 18 month when she started dropping foods and became texture specific
- ▶ Exhibited mealtime rigidity with strong preference towards certain containers or plates.
- ▶ Gagged at the sight of certain textures of foods (smooth purees) that led to occasional vomiting.

Assessment and Plan

- ▶ Presented to clinic with symptoms of coughing and choking on solid foods and liquids and smooth foods
- ▶ Preference towards smaller bites of food and smooth foods
- ▶ Food pocketing
- ▶ Food selectivity/refusal
- ▶ Excessive cow's milk intake
- ▶ High levels of parental stress related to feeding

Plan

- ▶ Upper GI endoscopy obtained- normal result
- ▶ Labs- consistent with iron deficiency anemia (likely due to excessive cow's milk intake)

Next steps

- ▶ Balance nutrition
- ▶ Feeding therapy

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Role of Registered Dietitian on Feeding Team

- ▶ Obtain detailed diet history and food frequencies—what adjustments could improve appetite and intake?
- ▶ Evaluate Growth trends and risk for malnutrition.
- ▶ Assess vitamin/ mineral deficiencies and need for lab testing.
- ▶ Calculate estimated calorie/protein/ fluid needs.
- ▶ Adjust enteral tube feedings—could schedule or formula itself help/hinder progress?
- ▶ Determine need for oral pediatric nutrition supplement or formula could benefit and what components could help gut comfort.

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Growth Charts for Lilly: Part of the Puzzle

*Note that many children with autism (up to 41%) are not underweight and instead are overweight - can lead to late referral

*Because diet is often so limited and rigid, periods of illness can result in significant weight loss/ takes longer to return to baseline

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Diet Recall -Lilly

<p>Initial Visit</p> <p>5:00 am: 8 ounces whole milk Breakfast: ½ cup strawberries or blueberries Lunch: fruit, 6 oz whole milk Dinner: one-brand potato chips(2 single serve bag), 10 grapes, cookies(6 specific brand choc chip), 6 oz whole milk Snack: grazes on gummies, fish crackers during the day After Dinner: 8 oz whole milk before bed 8 ounces whole milk overnight</p> <p>Fluid: 36 ounces whole milk, <8 oz water, 4 oz juice *Mealtimes-> 1 hour-walked around , vomited</p> <p>Initial Plan</p> <ul style="list-style-type: none"> -Trial of alternate plant- based supplement (due to constipation) and standard pediatric version -Liquid vitamin with iron ,Laboratory testing -Feeding Therapy 	<p>Three Month Follow-up</p> <p>6:00 am: 8 ounces standard pediatric oral supplement Breakfast: snack mix or cereal bar and 1 kiwi fruit, water Lunch: fruit (½ cup blueberries or strawberries), peanut butter sandwich, 6 oz whole milk Snack: supplement 4-5 oz Dinner: hot dog (no bun), slice garlic bread with cheese, 4 Tbsp corn/peas- working on broccoli, water After Dinner: supplement at bedtime 3-4 nights per week-6 oz supplement overnight (weaning off by diluting this with water) Fluid: 18 oz pediatric oral supplement, 12 oz water Pediatric Liquid vitamin with iron</p> <p>Follow-up Progress</p> <ul style="list-style-type: none"> -Mealtimes 30 minutes-will sit at table for 15 minutes -Working on structure -Timing of supplement (fading as she adds more food) -Expanding food group variety-protein/ F and V,
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Severe Food Selectivity=Risk for Deficiencies

Vitamin D	Calcium	Iron	Vitamin C	B Vitamins
<ul style="list-style-type: none"> • Helps regulate Calcium/ Phosphorus-maintains bone density • Immunological properties • Darker pigmented skin/ winter/ cloudy climate may all contribute to less absorption 	<ul style="list-style-type: none"> • Muscle contraction/nerve transmission • Blood clotting • Bone and teeth formation • Hormonal secretion 	<ul style="list-style-type: none"> • Synthesizes hemoglobin/ red blood cells- oxygenates blood from lung and tissues • Blood clotting • Electron Transport - synthesizes collagen, neurotransmitters • Aids cognitive functioning • Need for proper immune function 	<ul style="list-style-type: none"> • Formation, growth and repair of bone, teeth and connective tissues • Maintains blood vessels • Helps absorb iron • Burn/wound healing 	<ul style="list-style-type: none"> • Including Folate, Thiamine/ B6, B12 • Significant role in multiple neurologic functions in body- nerve function, DNA • Co-factor in formation and metabolism of cells. • DNA synthesis and cellular energy (allows energy from metabolism of fat, sugar and protein
<ul style="list-style-type: none"> • Muscle/ leg pains • Fatigue • Mood changes • Fractures/ Rickets 	<ul style="list-style-type: none"> • Muscle Cramps • Tingling in lips/finger/feet • SHF/ Aches in muscles • Confusion/ depression • Dry scaly skin/brittle nails 	<ul style="list-style-type: none"> • Numbness/tingling in hands/feet/ face • Muscle spasms esp in back and legs • Brittle hair and nails, dry scaly skin • Confusion/memory loss • Poor sleep/ irritability • Rickets/ Osteopenia/Osteoporosis • Pale Appearance 	<ul style="list-style-type: none"> • Bone pain • Impaired growth • Rash/ bruising/swelling • Anemia • Coarse hair • Bleeding gums • Mood changes and depression/ fatigue • Wound healing 	<ul style="list-style-type: none"> • Neurological impairments: abnormal balance, reflexes, memory and sensory loss • Lack of energy/fatigue (ex. tired in theatres/school) • Mouth ulcers • Muscle Weakness

Function
 Symptoms

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Nutrition Supplements

- ▶ Can benefit to fill in "gaps" (even if weight ok)
- ▶ Can send to school once daily if child not eating all day
- ▶ Takes pressure and focus off food/meal
- ▶ Cost is barrier-work with insurance DME's and "think out of box"
- ▶ Balance- timing and volume can determine success of feeding therapy progress
- ▶ Some evidence that food- based formula can help with GI comfort



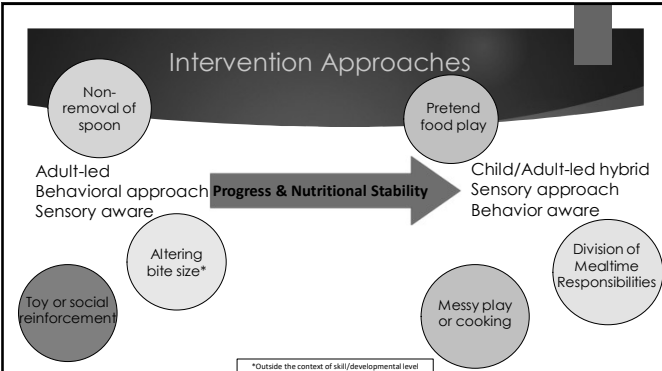
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Episodic Therapy

- ▶ 8 weekly sessions at consistent time and day of week
- ▶ Re-evaluation at session 8 to determine best next steps
- ▶ If another round of therapy is recommended, families take an intentional 2-4 month pause
- ▶ An important resting point for both child and caregivers to have consistent success. Goal is stability, not advancement!
- ▶ Benefits have included...
 - Improved attendance at sessions
 - Improved caregiver and child engagement in sessions and at home
 - Less burnout (for all involved)
 - Allows time to prioritize certain therapies instead of trying to balance
 - Frequent informal re-evaluation ensures that therapy techniques are updated to optimize progress, and appropriate referrals are made should progress plateau

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Intervention Approaches



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Common Therapy Pitfalls for Children with Autism



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Meeting Halfway

Lilly's Continued Progress

- ▶ Continues feeding therapy in the community as well as PT, OT, and ST
- ▶ Ongoing familial challenges
 - ▶ Recently switched to homebound school due to concern about her eating outside the home
 - ▶ Grazes/snacks throughout the day
 - ▶ Significant family concern about her growth
- ▶ Continues to be followed by UNC Feeding Team for medical management and nutritional monitoring

Functional vs Ideal Feeding

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Citations

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