Tools To Help Your Child’s Nutrition

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Severity of feeding difficulties may depend on genetics

- Focus of studies working toward linking severity of symptoms to genes.
  - **CFC syndrome**—Showed severe gastrointestinal symptoms irrespective of genetics. (McCormick et al.)
  - **Noonan’s Syndrome**—Protruding tongue found in those with SOS, RAF1, or SHOC2 mutations. (Digilio et al.)
Common feelings during meal times

- Many families express that they have failed because their child cannot effectively eat or drink independently

- Frustrations at meal times

- Hope that their child can one day eat a meal with the family and regain the social connection during meal time

- Anxiety due to poor weight gain

- Fear of medical devices offered for feeding therapy
Redirecting focus and setting goals

- Understand the difficulties with feeding
- Understand the growth potential
- Refocus energies to enhancing nutrition
  - Nutritional supplements
  - Vitamins
  - Medical feeding devices
Common features

- Poor suck, slow feeding, trouble swallowing, recurrent vomiting
- Heart disease affects feeding
- Musculoskeletal abnormalities (kyphosis and scoliosis) also make feeding difficult
- Possible anatomic abnormalities
  - Malrotation
  - High arch palate/ dental issues
  - Large tongue
Common features

- GI motility problems
- Endocrine problems
  - Hypothyroidism
  - Growth hormone deficiency
- Many need feeding tube in first year of life
Growth potential

- Initially large for gestational age
- And then loose large amount of weight within the first few days of life
- Then slow growth, severe feeding difficulties in childhood
- Short stature
Syndrome specific growth charts help with realistic growth goals.
Role of Feeding Team

- Obtain speech, physical, and occupational therapy to help improve feeding
- Can help children work with different textures of food and drink
- Observe feedings
- Speech therapists are present during barium swallow study to see what textures of foods are tolerated

Role of Gastroenterologist

- Work up and treatment other medical causes of poor feeding
  - Allergy
  - Reflux
  - Anatomical problems
  - Endocrine problems
  - Autoimmune conditions
  - Motility disorder
  - Malabsorption

Help with assessment to see if feeding tube is needed
Initial Work Up

- Assess swallowing ability
  - Barium swallow study
Initial Work Up

- Working up etiology of vomiting
  - Malrotation, webs, strictures, stenosis
    - Upper GI study
Initial Work Up

- Working up etiology of vomiting
  - Reflux
    - Treat with anti-reflux medicines
    - Impedence pH probe
    - Bravo pH probe
Initial Work Up

- Working up motility issues
  - Esophageal manometry
  - Antroduodenal manometry
  - Anorectal manometry
  - Colonic manometry
  - Gastric Emptying scan
Endoscopy to look for other causes of poor weight gain

- Upper endoscopy and colonoscopy for diagnosis of:
  - Allergic diseases
  - Celiac disease
  - Reflux esophagitis
  - Other autoimmune disease
Initial Work Up

- **Caloric nutrition**
  - Calorie count/ food diary
    - Work with a nutritionist to help you determine areas to improve
  - Trial of supplements
  - Choose foods with higher calories

![Food Diary](image)
Formulas that help with nutrition

- **Increase calories**
  - Concentrating formula
  - Supplemental formula (Pediasure, Boost, etc in older children)
  - Scandishake
  - Duocal
  - Benecalorie
  - Oils/ heavy creams
  - Microlipids/ MCT oil

- **Change formula if allergies found**
  - Hypoallergenic formula (Alimentum, Nutramigen, Neocate, Elecare, Peptamen, Pediasure Peptide)
Other diets and supplements

- **Blenderized diets**
  - Work with your nutritionist to ensure your child is getting the right amount of calories, fat, protein, vitamins, etc to grow.
  - Make sure you work with your nutritionist to make sure they are getting enough free water, to reach fluid needs daily

- **Helping with constipation**
  - Goal fiber should be 20-30 grams a day
  - Consider probiotics (lactobacillus, VSL 3, Culturelle)
  - Consult your doctor for laxatives (Miralax, lactulose, etc)
Vitamin Supplementation

- DEXA scan, monitor vitamin D and calcium
  - Reports of osteopenia

- Recommend a mult-vitamin supplement if not on liquid supplements

- New research on antioxidants?
  - Study by Anichini et al. on patients with Costello, Noonan's, Beckwith Wiedemann, and Prader Willi syndrome
  - Have excess oxidative stress that places patients at risk for cancer and other symptoms
  - Antioxidant therapy was developed after clinical observation of a child with Costello syndrome improved after parents supplemented his therapy with potassium ascorbate with ribose (PAR)
Further studies needed to define role for antioxidant therapy

- Supplemented these patients with potassium ascorbate with ribose (PAR) and monitored bloodwork every 3 months
  - Measured non protein bound iron, advanced oxidation protein products, total hydroperoxides, isoprostanes, thiols, and carbonyl groups

- Therapy was started at daily 150 mg of L-ascorbic acid, 3 mg D-ribose, and 300 mg potassium bicarbonate

- They showed improvement in the oxidative markers, with improvement of cardiac and skin manifestations
Be critical of the literature

- Interesting study on antioxidants, but use caution
  - Only one research group studying this topic, further studies needed
  - Small sample of patient enrolled, hard to generalize
  - They applying one therapy to various diseases like Beckwith Wideman syndrome, Prader Willi syndrome, etc
  - In the Costello syndrome cohort, only 3 patients were treated, 4th one died no reason stated
  - Unknown safety profile
Devices that help with nutrition

- Nasogastric tube (NG)
- Nasoduodenal tube (ND)
- Nasojejunal tube (NJ)
- Gastric tube (G tube)
- Gastro-jejunal tube (GJ tube)
- Jejunal tube (J tube)
Who places feeding tubes?

- Gastroenterologists
- Surgeons
- Interventional Radiologists
Should I go for the Nissen fundoplication?

- Considered if vomiting is severe
- Fundoplications are performed by surgeons
- May develop difficulty swallowing after this procedure
- Can slip later in life, vomiting may return
Does it mean that my child will never eat?

- Feeding rehab therapy is essential to work with textures and behaviors during meal times

- Can determine what textures are safe, or thicken liquids

- Reassessment at later time with modified barium swallow and other tests to see if it is safe to eat

- Each child is different and there is always a potential to improve feeding and nutrition
Accessorizing feeding tubes can be fun!

- Can accessorize feeding tubes
- Can buy devices that keep it secure, like belts
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Share your experiences

THE ONLY SOURCE OF KNOWLEDGE IS EXPERIENCE.

-Albert Einstein