Feeding and Nutrition Issues in Children with Down Syndrome

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KANSAS CITY

Multidisciplinary Down syndrome clinic

- Medical provider (Pediatrician/Adolescent Physician/Nurse Practitioner)
- Occupational Therapist (feeding therapist)
- Registered Dietitian
- Behavioral Psychologist
- Speech Pathologist
- Audiologist (ENT if needed)
- Social Work
- Genetic Counselor

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Infant Feeding (0-6 months)

- Breast milk and/or formula only
- Vitamin D supplementation
  - 400 IU/day
  - Breastfed or until taking 33 ounces of formula/day
  - D-vi-sol or Poly-vi-sol or Poly-vi-sol with iron
- Feeding on demand is optimal…however feeding on a schedule may be necessary

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Infant Feeding (6-9 months)

- Continue with breastmilk and/or formula
- Pureed foods about 6 months if:
  - Can hold head up steadily
  - Can sit with support in a highchair
  - Keeps food in mouth and swallows
- Iron source (ie:iron-fortified baby cereal)
- Purees are mainly for practice not nutrition/calories
  - Start with a few bites 1-2 times/day

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Infant Feeding (9-12 months)

- Continue with breastmilk and/or formula
- Soft/mashed table foods about 9 months if:
  - Has done well with pureed foods
  - No gagging/choking
- Iron source (ie:iron-fortified baby cereal, pureed meats)
- Purees/table foods are mainly for practice not nutrition/calories

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Infant Feeding Difficulties

- Congenital heart defects
- Poor oral-motor skills (thickener, tube feedings)
- Constipation
- Reflux
- Content/Sleepy infant
- Inadequate intake = Poor growth

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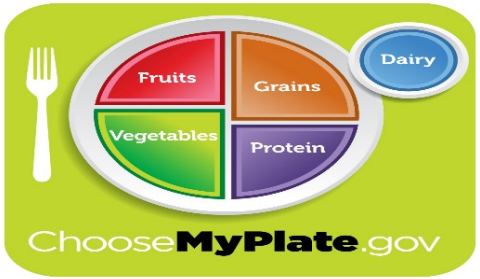
Child Feeding

- Transition to milk (if eating a variety of food groups)
  - Practice with open cup or straw cup
  - Whole milk from 1-2 years, Low fat milk > 2 years
- 2-3 dairy servings, 3-5 ounces grains, 5+ fruit/veg servings, 2-4 ounces meat/protein, limit juice to 4-6 ounces
- Adequate calcium, iron, vitamin D, zinc



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Child Feeding

- Structured meals/snacks
  - At the table, no distractions
  - Spaced 2-4 hours apart (no grazing)
  - 3-4 food groups per meal, 2-3 food groups per snack
  - Family meals, avoid “short order cooking”
- Multivitamin/mineral—hard chewable instead of gummy

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Child Feeding Difficulties

- Texture
- Oral-Motor skills
- Cup transition
- Picky eating/Behavioral eating
- Constipation
- Overweight/Obesity
  - Low basal metabolic rate
  - low physical activity (some)
  - poor satiety and recognition of fullness (some)
- Thyroid disorders
- Diabetes
- Celiac Disease

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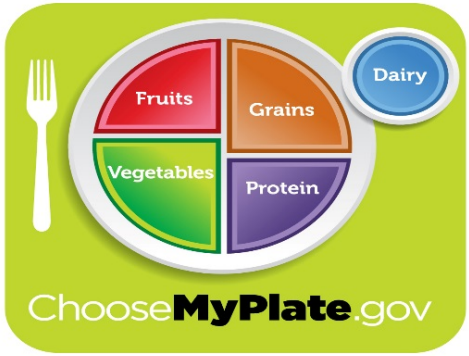
Adolescent Feeding

- Structured meals/snacks
- 3 dairy servings, 5-8 ounces grains, 5+ fruit/veg servings, 5-7 ounces meat/protein, limit juice to 4-6 ounces
- Adequate calcium, folate, vitamin D, zinc



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Adolescent Feeding Difficulties

- Texture
- Picky eating/Behavioral eating
- Constipation
- Overweight/Obesity
  - 10-20% lower calorie needs
  - low physical activity
  - poor satiety and recognition of fullness
- Thyroid disorders
- Diabetes
- Celiac Disease

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Difficulties with eating

- Infants and children with Down syndrome have (structural) and (functional) differences in the mouth and throat areas that make it more difficult for them to make precise movements

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Difficulties with eating

- Anatomical differences that are seen include :
  - small and narrow upper jaw
  - high palatal arch
- Physiological differences that are seen include:
  - low muscle tone
  - weak oral facial muscles
- These combinations result in open mouth posture, tongue protrusion, and hyposensitivity

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Picky Eaters

- Decreased range or variety of foods but will eat >30 foods
- Foods lost due to burn out usually re-gained after 2 weeks
- Tolerates new foods on plate and usually can touch or taste
- Eats >1 food from most all food texture groups or nutrition groups
- Adds new foods to repertoire in 15-25 steps
- Typically eats with family but frequently eats different foods then family
- Sometimes reported as “picky eater” at well child check

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Problem Feeders

- Restricted range or variety of foods, usually <20
- Foods lost are not re-acquired
- Cries/"falls apart" with new foods
- Refuses entire categories of food textures or nutrition groups
- Adds new foods in >25 steps
- Usually eats different foods than family and often eats alone
- Persistently reported as "picky eater" across multiple well child checks

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Healthy Feeding Relationship

Caregiver's job:

- What foods are offered (ideally MyPlate)
- When foods are offered (scheduled)
- Where foods are offered (ideally at the table, no distractions)

Child's job:

- If foods are eaten (avoid forcing/bribing/coaxing)
- How much is eaten (within reason)

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Weight Control Ideas

- Prevention—much easier than treatment
- Establish family rules for healthy eating
- Structured eating—3 meals and 1-2 snacks
- Avoid “grazing”
- Avoid using food as reward
- Get Kids in the Kitchen

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Weight Control Ideas

- Non flavored, low fat milk with meals
- Non sugared drinks between meals—**water** is best
- High fiber, low calorie snacks (fruit, vegetables, popcorn)
- Limit main entrée and side dishes to 1 serving
- Unlimited servings of fruits and vegetables

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Kids in the Kitchen

- helping choose menu items
- setting table
- tearing lettuce leaves
- cutting fruits/vegetables (practice with playdough
- boiling water
- pouring ingredients in a bowl
- breaking spaghetti noodles in half, etc
- pouring drinks

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Questions for School

- Breakfast at home and school?
- Allowed more than one entree serving?
- Chocolate milk and juice?
- Are snacks necessary, if so--how many snacks at school/day? Snacks at afterschool care?
- What is the reward system?—is it candy?

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Medical Issues Related to Feeding

- Gastroesophageal Reflux/Disease (GER or GERD)
- Aspiration
- Celiac disease
- Constipation

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New Growth Charts

- https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/growth-charts.html
- Released December 2015
- 0-36 months
  - Weight, length, and weight for length
- 2-20 years
  - Weight and height (BMI charts not released)

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Why no BMI charts?

- Do not reflect a healthy/ideal BMI
- Overweight/obesity could be under diagnosed
- CDC recommendation: 2000 CDC BMI growth chart
  - >85th%ile is overweight
  - >95th%ile is obesity

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Alternative Therapy

- A treatment not proven to be:.
  - effective or ineffective
  - safe or unsafe
- Anecdotal rather than Evidenced Based
- Not typically supported by experts in that field
- Claims: improved health, growth, immune function, cognition, changes in facial features

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Alternative Therapy Concerns

- Cost
- No standardization of ingredients
- Not enough data; few randomized controlled trials
- Improper expectations
- Side effects and toxicity

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“Down syndrome” supplements

- Warner’s Hap Caps (Warner House in California)
- MSB (NutriChem Labs in Ontario)
- Nutrivene family of products (International Nutrition in Maryland)
- Piracetum (UCB Pharma in Belgium)
- Dimethyl Sulfoxide (DMSO)
- Ambrotose (Manna Tech in Australia)
- **No evidence to support these products**

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What if my child doesn't eat anything that is squishy (no purées), just lacking variety in food intake

- Work on dipping; depending on how expansive the limit
  - are they an infant and not adding purees and soft cubes that would be developmentally appropriate, or are they 3 and just don't care for purees specifically?
  - The first would need oral motor therapy for tongue lateralization and sensory. The second I wouldn't worry about a kid not liking soft and squishy if they eat an otherwise full diet.

If kids with limit themselves to lots of purées (with a few favorite foods that involve chewing), what does this indicate?

- Likely indicates oral motor delay - tongue lateralization.
- Additionally the more they gag then we have a behavioral/anxiety based on aversive experiences.
- Likely needs feeding therapy

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We are stuck on soft mechanical diet (tone related), how can we get to the next level?

- Likely indicates oral motor delay - tongue lateralization.
- Additionally the more they gag then we have a behavioral/anxiety based on aversive experiences.
- Need feeding therapy. Additionally this could be related to tone - then using a chewy tube to strengthen would be good.

Overstuffing their mouth - besides limiting what is on their plate, how can you make them stop?

- Likely indicates poor sensory awareness - increasing flavor of food (adding dip or seasonings or lemon) will help increase their awareness.
- Also offering dry crunchy (goldfish) with a food that is hard to chew (meat) at the same time (putting goldfish in mouth with a small cube of steak) will increase awareness based on sound of the food
- Offering less volume on the tray (1-3 bites at a time) and encouraging a drink between bites to clear mouth.

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Is Gluten Free or Dairy Free optimal?

- Gluten free and dairy can be optimal (however not necessary unless there is an allergy/intolerance or medical diagnosis to follow)
  - Adequate micronutrients?—recommend a multivitamin/mineral
  - Adequate fiber?—gluten free grains often low in fiber
  - Calcium and vitamin D—fortified milks/foods

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