Nutrition and Feeding Related Concerns in People with Down Syndrome

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Objectives

• Participants will be able to:
  – Describe differences in the nutrition needs of people with Down syndrome
  – Name feeding-related concerns in people with Down syndrome
  – Explain techniques to improve meal-time behaviors and feeding problems related to sensory awareness or texture aversions
  – Describe nutrition-related risk factors more common to this population

Children’s Mercy Hospital
Down Syndrome Clinic

Our Team
• Pediatric specialist
• Audiologist
• Behavioral psychologist
• Genetic counselor
• Occupational therapist
• Registered dietitian
• Social worker
• Speech pathologist
• Team coordinator
Growth

Caloric Needs

• Daily calorie needs are ~10-15% lower than children of the same age without Down syndrome
  – Lower metabolic rate due to lower muscle tone
  – Activity levels
• Monitoring growth
  – Down Syndrome vs CDC Growth Chart
  – Growth rate is slower

Nutrient Needs

• No special recommendations for vitamin and mineral intakes for people with Down syndrome
• General population- different age groups have different concerns
  – Infants: Iron, Vitamin D
  – Toddler: Calcium, Vitamin A, Folate, Iron
• Zinc deficiency most common in all age groups
What about supplements?

- Typically recommend a daily chewable multivitamin
- Individual needs vary
- Others often recommended
  - Fish oil
  - Vitamin D
  - Calcium
  - Probiotic

Justification for Supplementation

- Metabolic differences in people with Down syndrome
  - Folate metabolism
  - Zinc metabolism
- Increased oxidative stress
  - Increased oxidative enzymes expressed

Trisomy 21

[Chromosome image]
Concerns with Supplementation

- Cost of the treatment
- No standardization of ingredients
- Not enough data, because there are no comprehensive studies
- Improper expectations of parents about possible effects

How to Get a Child to take Supplements

- Be enthusiastic and positive
- Crush vitamin and mix into a food or drink
  - Applesauce, pudding, yogurt
  - Small amount of juice
- Follow the vitamin with a favored “chaser”
- Make the vitamin a routine
- Create a sticker chart or other reward-based motivator
Common Feeding Problems in People with Down Syndrome

Progression of Oral Motor Skills

• Concerns
  – Muscle tone and strength in lips and mouth
  – Tongue coordination
  – Coordinating mouth movements for swallowing
  – Sensitive gag reflex
  – Delayed eruption of teeth

Muscle Tone and Strength in the Lips and Mouth

• Difficulty with lip closure for bottle feeding or cup drinking
  – May be slow to progress to cup
• Difficulty with lip closure for spoon feeding
  – May be slow to progress from breastmilk/formula to baby/table foods
  – Drinking versus eating calories
  – May require Pediatric formula to meet needs
• Poor oral strength or fatigue with chewing
  – Although not ideal, a pureed diet can be nutritionally adequate
Activities that Improve Strength in the Lips and Mouth

- Use physical prompts with the index finger on the upper lip to cue child to close lips on a spoon or cup
- Strong tastes in small amounts on tip of the spoon to facilitate lip closure
- Use whistles, straws and lip games
- Vibration for sensory stimulation on the lips and cheeks
- Wrap crunchy/flavorful foods in gauze and have child practice chewing
- Offer a variety of chewy tubes and oral toys
- Flavored tongue depressors- hold between the lips and shake slightly while saying “mmmmmm”

Tongue Coordination

Concerns:
- Excessive tongue protrusion-pushing the tongue out
- Difficulties with tongue retraction-pulling the tongue back
- Decreased tongue lateralization –moving the tongue side to side

Activities to Improve Tongue Movement

- **Thermal stimulation:** intense cold facilitates tongue retraction; tongue wants to find and move the cold sensation
- **Hide-a-seek:**
  - place chewy tube in different places in the mouth; have the child try to find it with their tongue or
  - move the tube from side to side with the tongue
- Put food on the outer edges of the lips and use tongue to remove it
- Place toothette on the tongue and ask the child to “squeeze” the sponge with the tongue
- Resistive straw games that work the tongue elevation and retraction
Sensory Awareness

• Under-awareness
  – May not chew foods well, swallow large amounts of food at a time
  – Overstuffing of the mouth
  – Difficult to stimulate swallow

• Over-awareness
  – Texture or temperature problems with foods
  – Usually have problems with other areas as well
  – Influence what foods are/ are not eaten

Activities that Improve Sensory Awareness

• Offer high sensory foods such as sour, sweet, crunchy
• Use seasonings
• Homemade foods offer more taste/flavor and stimulation because they have multiple textures
• Vibration using a Z-vibe or Nuk brush
  – Rub gums, insides of cheeks and tongue before meals
• Tummy time for babies: mouth hands, blanket, or other toys
  – Offer toys with different textures for oral exploration
• Thermal stimulation
  – Alternate cold/warm
  – Frozen fruits or purees

Healthy Feeding Relationship and Mealtime Behaviors
**Divide Eating Responsibilities**

**Parent’s Responsibilities**
- Decide what foods to offer at meals and snacks
- Set regular meal and snack times
- Provide meals or snacks at the kitchen/dining table only (without TV)

**Child’s Responsibilities**
- Decide if he/she will eat
- Decide how much he/she will eat of foods served
- Be present at family meals
- Eat at the kitchen/dining table only

**Healthy Habits**

- Parents who eat healthfully and take care of their bodies set a good example for their children
  - A majority of children’s eating habits are learned by example
- Not so healthy eating habits:
  - Pressuring, bribing
  - Forcing your child to eat
  - Short order cooking

**Definition of Behavioral Feeding Issues**

- Behavior that interferes with the development of appropriate oral intake
  - Not advancing skills
  - Eating too much
  - Eating the wrong things
- Behavior considered unacceptable at meals
  - Disruptive behavior
  - Throwing things
Assumptions

• Behavior is learned, a result of experience
• Behavior serves a purpose
  – If behaviors could talk, what would your child’s behavior say?

Function and Purpose of Behavior

• Get something—Positive reinforcement
  – Social (attention, access to tangible reinforcers)
  – Automatic (sensory stimulation)
• Escape/avoid something—Negative reinforcement
  – Social (escape from demand)
  – Automatic (pain reduction)
• How to intervene depends on the function of the behavior.

Consequences of Behaviors

• Parental attention and social praise are powerful positive consequences that influence the behavior of young children
  – increase the attention to desired behaviors
  – decrease the attention to unwanted behaviors
• A stronger consequence for some behaviors may be necessary
  – Time out
Tips for Mealtime Success!

• Keep meals as pleasant and as free of tension as possible
  – don’t attempt to influence how much your child eats
  – limit distractions
• Serve smaller portions than you expect your child to eat and let him ask for more
  – Large portions can be discouraging
  – Let your child eat foods in any order or combination

Tips for Mealtime Success!

• Allow your child enough time to eat, but don’t let mealtimes drag on indefinitely
  – Set a timer for 20 minutes
• Don’t let your child fill up on food between meals
  – Scheduled snacks versus grazing
• Never give food as a reward or withhold it as a punishment
  – Avoid messages that cause your child to confuse food with love or affection

Tips for Mealtime Success!

• Serve foods that let your child practice fine motor skills
  – Ex. shredded cheese, diced fruit, peas, or cereal
  – Dipping fries in ketchup or fruit slices in yogurt will foster exploration of food
• Offer choices within limits. For example, ask, “Would you rather have cereals or toast this morning?”
Tips for Mealtime Success!

- When a new food is introduced, encourage a test bite
  - Never require that your child eat all of the unfamiliar food
  - Offer new foods frequently, along with old favorites, even if they have been refused at other meals

Tips for Mealtime Success!

- Respect your child’s likes and dislikes—we all have individual food preferences
  - Your child refuses cooked vegetables?
  - Serve them diced and raw with dip for snacks
  - Grate them into casseroles, soups, stews, meat loaf, omelets, breads, or spaghetti sauce
- Don’t categorize food as good or bad
  - All foods eaten in moderation can be part of a healthful diet

Getting Children to Try New Foods

- One food at a time, small portions (~1/2 teaspoon)
- Allow children the option **not** to swallow
- Give a food many tries
  - Offer a preferred food with a non-preferred food
  - Try a new presentation of the food
- Try a new food with siblings or peers that are “good tasters”
- Involve children in the preparation of food
Nutritional Risk Factors

• Congenital Heart Disease
• Gastroesophageal Reflux
• Celiac Disease
• Constipation
• Obesity
• Hypothyroidism

Constipation

• Low fluid/fiber intake
• Poor muscle tone
• Decreased activity
• Hypothyroidism
• Hirschsprung’s disease

Treatment of Constipation

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Obesity

- Common in people with Down syndrome
  - Lower muscle tone and calorie requirements
  - Tendency to be sedentary
  - Higher incidence of feeding problems, pickiness

How much should my child be eating?

The Plate Model

- Fruits
- Meat, protein
- Vegetables
- Bread, starch
- Lunch or dinner

- 1 cup of fruits: 1/4 of plate
- 1 cup of vegetables: 1/4 of plate
- 1 cup of lean meat: 1/4 of plate
- 1 cup of bread or starch: 1/4 of plate
- 1 cup of milk or dairy: 1/4 of plate
Jump Start Your Family

• What are you doing well now?
• What can you improve?
• Set small goals that are achievable (SMART)
  – specific (time, amount, days of week)
  – measurable (minutes of activity per day)
  – realistic (one you are sure you will do)

Sample Goals

• We will eat 3 family meals at home each week with the TV off
• We will eliminate all sugary beverages from our home
• We will take a family walk twice weekly for the next month
• We will serve 2 vegetables with each dinner for the next 3 weeks
Nutrition resources

- USDA Food and Nutrition Information Center  www.nal.usda.gov/fnic
- US Department of Agriculture (select promoting good nutrition)  www.usda.gov
- Parents -24 hour carrot press  www.nutritionforkids.com
- More matters 5 a day  www.fruitsandveggiesmorematters.org
- Someone’s in the Kitchen with Mommy - by Elain Magee, RD  
  (NTC/Contemporary Publishing – 1997)
- Quick Meals for Healthy Kids and Busy Parents - Sandra Nissenberg, MS, RD, 
  Margaret Bogle, PhD, RD and Audrey Wright, MS, RD (Wiley, John and Sons, Inc – 1995)
- Mom’s guide to Meal Makeovers - Janice Newell Bissex, MS, RD and Elizabeth Weiss, MS, RD.  
  (Broadway Books, 2004)
- How to Teach Nutrition to Kids, 3rd Edition - Connie Liakos Eers, MS, RD  
  (24 Carrot Press, 2006)
- Childe of Mine: Feeding with Love and Good Sense - Ellyn Satter, MS, RD  
  (Ball Publishing Co. – 2000)