



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





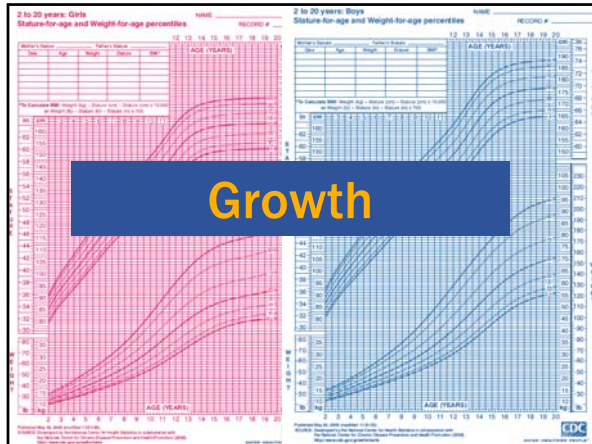
Children's Mercy Hospital Down Syndrome Clinic

Our Team

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

our mission is to improve the quality of life of individuals with down syndrome







Caloric Needs

- Daily caloric 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



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Justification for Supplementation

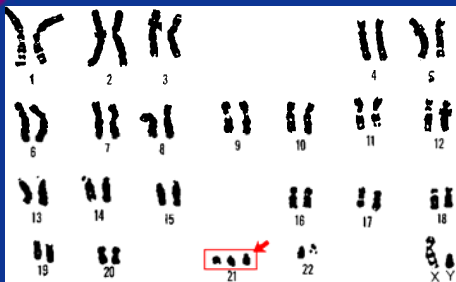
- Metabolic differences in people with Down syndrome
 - Folate metabolism
 - Zinc metabolism
- Increased oxidative stress
 - Increased oxidative enzymes expressed

Biogerontology 2006; 7 (4): 211-220
Clin Chem Lab Med 2006; 44 (3): 306-10

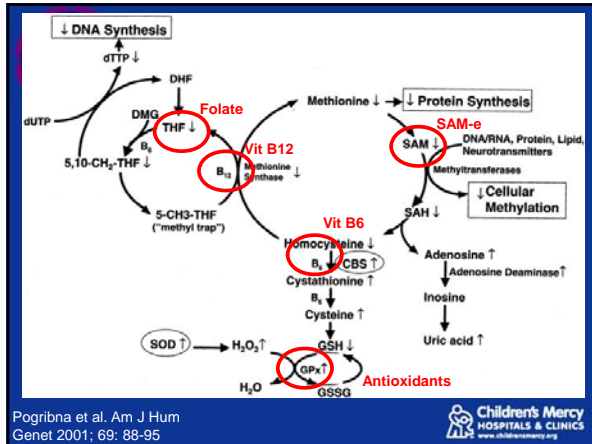
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Trisomy 21



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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

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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

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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 “mmmmm”





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-n-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 (~½ 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



Murat, B., Stewart, G., Rea, J. The Home Treatment Encyclopedia.
<http://www.home-treatment-encyclopedia.com/constipation.html>





Treatment of Constipation

Diet	Fiber- fruits, vegetables, whole grains Fluid
Fiber	Cellulose- Citrucel® Psyllium- Metamucil®
Probiotics	Various Yogurts Culturelle® for Kids EnvoraKids® FloraStor® Kids Probiotic Garden of Life®
Stool Softeners	Mineral Oil- Kondremul® Polyethylene Glycol- Miralax® Lactulose Sorbitol- Karo® Syrup
Laxatives	Senna Bisacodyl





Obesity

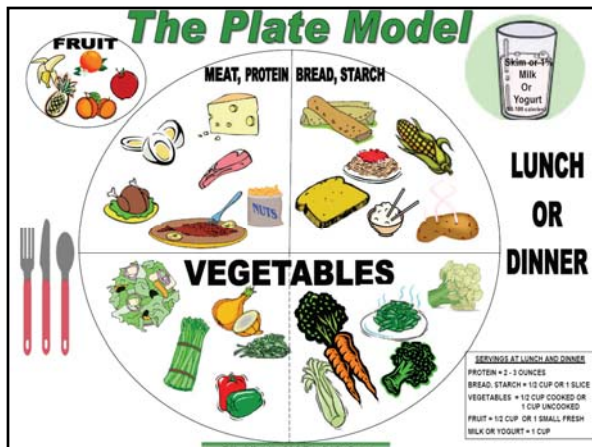
- Common in people with Down syndrome
 - Lower muscle tone and calorie requirements
 - Tendency to be sedentary
 - Higher incidence of feeding problems, pickiness

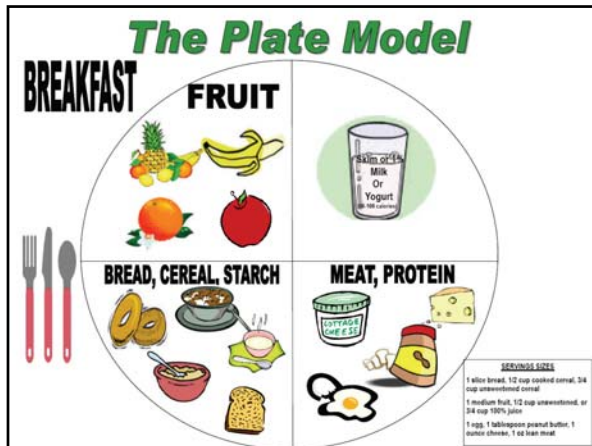





How much should my child be eating?










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)
- *Child of Mine: Feeding with Love and Good Sense* - Ellyn Satter, MS, RD (Bull Publishing Co. – 2000)