

# **Nutrition and Feeding Related Concerns in People with Down Syndrome**

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## 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

#### 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.

#### 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
- 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 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 p 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

Child's Responsibilities

- Decide if he/she will eat

- Decide how much he/she

- Set regular meal and snack times

- Provide meals or snacks at the kitchen/dining table only (without TV)

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

– Most 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?

#### 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 the familiar 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 Celiac Disease
- Constipation
- Obesity
- Hypothyroidism

#### Constipation

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

#### Treatment of Constipation

Diet Fiber- fruits, vegetables, whole grains

Fluid

Fiber Cellulose- Citrucel®

Psyllium- Metamucil®



Probiotics Various Yogurts

Culturelle<sup>®</sup> for Kids

EnvoraKids<sup>®</sup>

FloraStor<sup>®</sup> Kids Probiotic

Garden of Life<sup>®</sup>

Stool

Softeners

Mineral Oil- Kondremul<sup>®</sup>

Polyethylene Glycol- Miralax<sup>®</sup>

Lactulose

Sorbitol- Karo<sup>®</sup> 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

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

## 15 Nutrition resources

- USDA Food and Nutrition Information Center [www.nal.usda.gov/fnic](http://www.nal.usda.gov/fnic)
- US Department of Agriculture (select promoting good nutrition) [www.usda.gov](http://www.usda.gov)
- Parents -24-hour carrot press [www.nutritionforkids.com](http://www.nutritionforkids.com)
- More matters 5 a day [www.fruitsandveggiesmorematters.org](http://www.fruitsandveggiesmorematters.org)
- Someone's in the Kitchen with Mommy – by Elain Magee, RD  
(NTC/Contemporary Publishing (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  
(Bull Publishing Co. – 2000)