



DOWN SYNDROME

Nutrition Issues

NUTRITION ISSUES

- Growth Issues
- Feeding
 - Oral anomalies
 - Breastfeeding
 - Transition to foods
- Weight Management
- Other health concerns
 - Celiac disease
 - Diabetes



GROWTH ISSUES

- Growth Charts

- <http://www.growthcharts.com/>

- Using growth charts specific to Down Syndrome facilitates detection of children who are crossing centiles

- A fall in growth velocity may reflect treatable conditions such as
 - Hypothyroidism
 - Celiac disease



GROWTH ISSUES

- Decreased linear growth rate
 - Those raised in the community appear to be taller than those raised in institutions
 - Females
 - 1.5-2.5 standard deviations (SD) below population mean until age 12
 - Fall to 3 SD below mean after age 12
 - Males
 - 2-3 SD below the mean to age 13
 - 2-4 SD below the mean age 13 to adulthood



GROWTH ISSUES

- From late infancy children with Down syndrome show a relative increase in
 - Mean weight-for-length and weight-for-height
 - BMI (weight/stature²)
- Excessive weight is a problem in adulthood
 - One study of individuals with Down syndrome showed
 - Less than 15% were within desirable with range
 - 20-30% were overweight, and
 - Almost 50% were obese



GROWTH ISSUES

- Monitor linear growth using growth charts specific for Down syndrome.
- Monitor weight-for-length/stature and BMI-for-age using the CDC growth charts
 - Down syndrome charts are based on data from actual children and reflect elevated weight for height status
 - <http://www.cdc.gov/GrowthCharts/>



CALCULATION OF ENERGY REQUIREMENTS FOR CHILDREN WITH DOWN SYNDROME

- Children 5 to 11 years
 - 14.3 kcal/cm for girls
 - 16.1 kcal/cm for boys

Lucas BL, ed. *Children with Special Health Care Needs: Nutrition Care Handbook*. Chicago, IL. American Dietetic Association; 2004.



FEEDING ISSUES

- Oral anomalies associated with Down syndrome
 - Reduction in the length of the palate
 - Tendency to protrude the tongue and to mouth breathe
 - Results in cracked lips and fissured appearance of tongue



FEEDING ISSUES

- Dental anomalies in individuals with Down syndrome
 - Microdontia
 - Hypodontia
 - Tooth agenesis
 - Delayed eruption of primary dentition
 - Delayed eruption of the permanent dentition



FEEDING ISSUES

- Other oral/dental anomalies
 - Frequent malocclusions
 - Frequent temporomandibular joint dysfunction
 - Platybsia
 - Bruxism
- Gingivitis and peridontitis are common in individuals with Down syndrome
- Other issues that affect feeding
 - Poor muscle tone/weak musculature
 - Poor oral motor coordination
 - Poor coordination of suck/swallow/breathe sequence
 - Poor lip seal



FEEDING ISSUES

- Breastfeeding is recommended for all the usual reasons
- Breastfeeding a child with Down syndrome can be easy or difficult
- Challenges include
 - The baby may fatigue early in feeding
 - The baby may have problems “latching on”
 - The baby may have a weak or poor suck
- Assistance from a lactation consultant can be very helpful to find practical strategies



FEEDING ISSUES

- Transition from breast milk/formula to other foods
 - May be slower or more difficult due to low tone or poor oral motor coordination
- Feeding issues can develop during transitions to table food and family meals
 - Picky eating
 - Food jags



CUES TO LOW ORAL-MOTOR TONE

- Prolonged bottle use or breastfeeding
- Desires sweets and other low nutrient foods (fries, chips...)
- Slow to progress through food textures
- May not enjoy eating in general



CUES TO PICKY EATING

- Skipping food groups
- Variable eating: What he will eat changes with the environment
- Seeks attention or control during mealtimes



CUES TO FOOD JAGS

- Requesting the same one or two items every day, for every meal, if given the option
- Will accept other foods, if not given a choice or given structured choices
 - “Do you want an apple or an orange?” vs
 - “What do you want to eat?”
- Food selected lasts for a period of time, then is replaced by another absolute favorite



FEEDING ISSUES

- Feeding problems may contribute to other health issues
 - Poor chewing may result in swallowing of foods whole or only partially chewed which may contribute to
 - Constipation or
 - Risk of aspiration
 - Fatigue or poor eating skills may reduce the amount of food consumed which can lead to malnutrition
- Evaluation by and assistance from a feeding therapist or interdisciplinary feeding team would help families work through some of these feeding difficulties.



CONSIDER A MULTIVITAMIN SUPPLEMENT IF YOUR CHILD

- Is a picky eater
- Is having trouble with food textures
- Is on a calorie restricted diet for obesity, or
- Complains of fatigue and appears more listless than usual

Medlen JG. *The Down Syndrome Nutrition Handbook*.
Phronesis Publishing, LLC. , Lake Oswego, OR, 2006.



WEIGHT MANAGEMENT

- The prevalence of overweight and obesity is high in individuals with Down syndrome beginning in childhood
- Food intake does not appear to be increased in individuals with Down syndrome compared to their peers
- Contributing factors may include
 - Decreased resting energy expenditure
 - Reduced physical activity



WEIGHT MANAGEMENT

- A recent study reported increased leptin levels for percent body fat for a group of children with Down syndrome compare to a control group of unaffected siblings.
- No significant differences were reported in
 - Ghrelin
 - Insulin or glucose levels
- Magge SN, O'Neill KL, Shults J, Stallings VA, Stettler N. Leptin Levels among Prepubertal Children with Down Syndrome Compared with Their Siblings. *J Pediatr* 2008;152:321-6.



WEIGHT MANAGEMENT

- Leptin, a hormone secreted by adipocytes, acts in the hypothalamus to suppress appetite and control body weight.
- It is postulated that obese individuals have some degree of leptin resistance.
- Ghrelin is an appetite-enhancing hormone
- Insulin and glucose levels are measures of insulin resistance

Magge SN, O'Neill KL, Shults J, Stallings VA, Stettler N. Leptin Levels among Prepubertal Children with Down Syndrome Compared with Their Siblings. *J Pediatr* 2008;152:321-6.



WEIGHT MANAGEMENT

- Medical Conditions that Contribute to Weight Gain
 - Hypothyroidism
 - Gastroesophageal reflux
 - Medications that promote weight gain as a side effect



WEIGHT MANAGEMENT

- Medical Conditions that Contribute to Weight Loss
 - Undiagnosed diabetes
 - Undiagnosed celiac disease
 - Hyperthyroidism
 - Cancer
 - Infection
 - Unrepaired heart defect
 - Gastroesophageal reflux



WEIGHT MANAGEMENT

- Setting Goals for Weight Management
 - 3 types of weight-related goals. Goals aimed at:
 - Stopping weight gain
 - Maintaining current weight
 - Weight loss



WEIGHT MANAGEMENT

- Structure for goal setting
 - Set weekly goals
 - Set one goal for food-related behavior and one for activity
 - Set daily goals that lead to the weekly goal
 - Create a way to keep track of success.
 - Visual methods of record keeping are very successful.



A WELL-DESIGNED WELLNESS PLAN INCLUDES

- FUN
- Social component
- Variety
- Challenging but not competitive activities
- Precautions to decrease risk of injury
- Appropriate goals
- Rewards
- Opportunities to compete against one's own personal best, but not others
- Family and friends
- Support of family and the medical community



OTHER HEALTH ISSUES

- Celiac Disease
- Diabetes



CELIAC DISEASE

- A permanent sensitivity to gluten and related proteins in barley and rye
- Occurs in genetically susceptible individuals
- An immune-mediated enteropathy defined by characteristic changes seen on intestinal biopsy



CONDITIONS ASSOCIATED WITH AN INCREASED PREVALENCE OF CELIAC DISEASE

- Type 1 diabetes
- Autoimmune thyroiditis
- Down syndrome
- Turner syndrome
- Williams syndrome
- Selective IgA deficiency
- First degree relatives of celiac patients



CELIAC DISEASE

- Prevalence of celiac disease in children between 2.5 and 15 years of age in the general population is 3 to 13 per 1000 children or approximately 1:300 to 1:80 children.
- The prevalence of celiac disease in individuals with Down syndrome is between 5% and 12%



CELIAC DISEASE

- Individuals with celiac disease can be symptomatic with gastrointestinal and non gastrointestinal symptoms.
- Celiac disease can also occur in some asymptomatic individuals who have conditions that are associated with celiac disease.



GASTROINTESTINAL MANIFESTATIONS OF CELIAC DISEASE

- Diarrhea with failure to thrive
- Abdominal pain
- Vomiting
- Constipation and abdominal distension



Signs and Symptoms of Celiac Disease

<i>Sign or symptom</i>	<i>Prevalence in patients with celiac disease (%)</i>
Common	
Diarrhea	45 to 85
Fatigue	78 to 80
Borborygmus	35 to 72
Abdominal pain	34 to 64
Weight loss	45
Abdominal distention	33
Flatulence	28
Uncommon or rare	
Osteopenia or osteoporosis	1 to 34
Abnormal liver function	2 to 19
Vomiting	5 to 16
Iron-deficiency anemia	10 to 15
Neurologic dysfunction	8 to 14
Constipation	3 to 12
Nausea	4

NON-GASTROINTESTINAL MANIFESTATIONS OF CELIAC DISEASE

- Dermatitis herpetiformis
- Dental enamel hypoplasia of permanent teeth
- Osteopenia/osteoporosis
- Short stature
- Delayed puberty
- Iron-deficient anemia unresponsive to treatment with oral iron (well documented in adults only)





DERMATITIS HERPETIFORMIS

Presutti RJ,
Cangemi JR,
Cassidy HD, Hill
DA. Celiac
Disease. *Am Fam
Physician*
2007;76:1795-802



SCREENING FOR CELIAC DISEASE

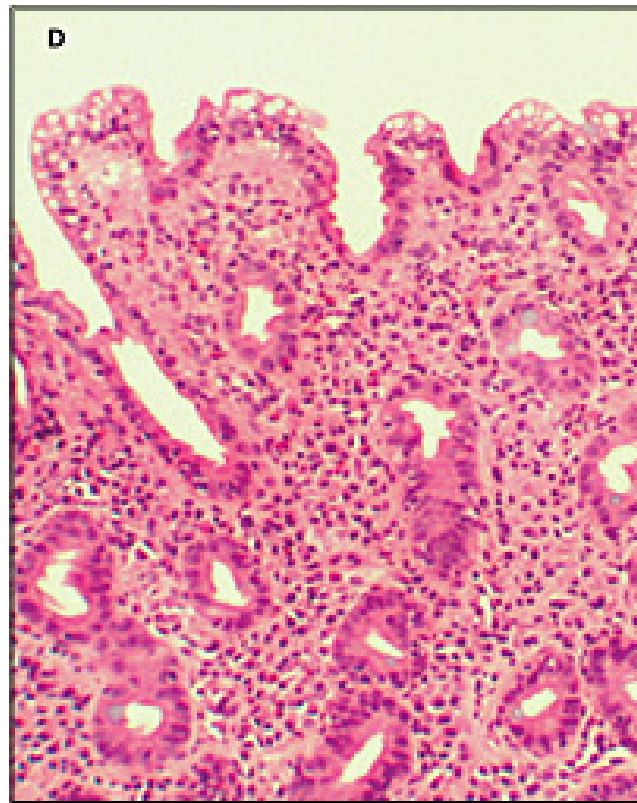
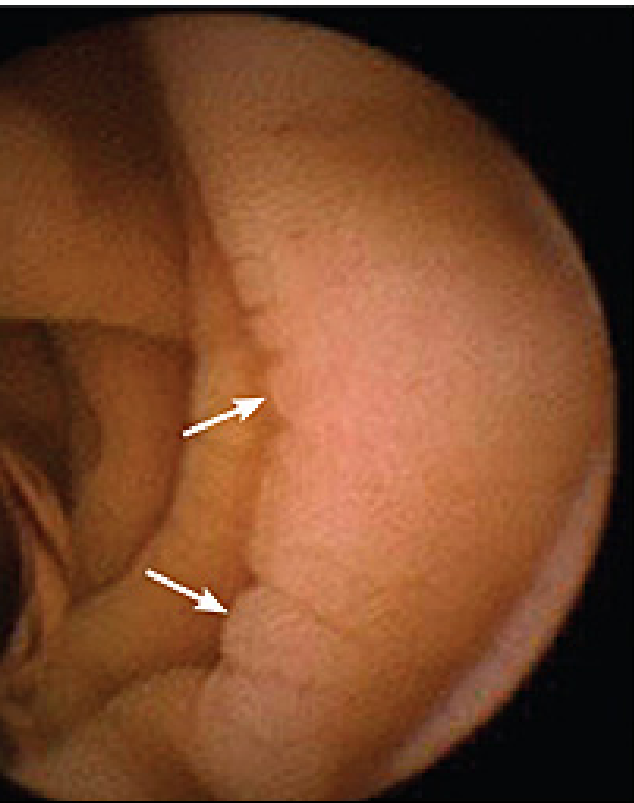
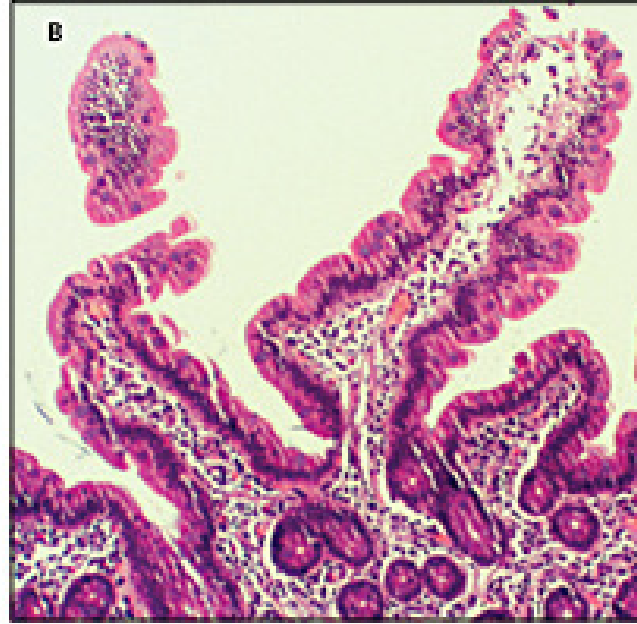
- Serological screening for at risk individuals
- Individuals with negative serological screening who belong to certain at risk groups should be considered for repeat testing at intervals:
- Type 1 diabetes
- First-degree relatives of individuals with celiac disease
- Individuals with Down syndrome



DIAGNOSIS OF CELIAC DISEASE

- Confirm diagnosis with intestinal biopsy
- Treatment should only be started after diagnosis is confirmed.





CELIAC DISEASE EVALUATION

- A. Endoscopic photo of normal small intestine
- B. Biopsy specimen of normal small intestine
- C. Small intestine with celiac disease
- D. Biopsy specimen of celiac disease



TREATMENT OF CELIAC DISEASE

- Treatment with a gluten free diet is recommended for all symptomatic children with intestinal abnormalities characteristic of celiac disease
- Treatment with a gluten free diet is also recommended for asymptomatic children who have a condition associated with celiac disease and characteristic histologic findings on small intestinal biopsy.



TREATMENT OF CELIAC DISEASE

- It is not clear what the threshold is for gluten consumption below which no harm occurs
- There is evidence that consumption of even small amounts of gluten on a regular basis by individuals with celiac disease can lead to mucosal changes on intestinal biopsy



STANDARDS FOR “GLUTEN-FREE” FOODS

- **CODEX STANDARD FOR FOODS FOR SPECIAL DIETARY USE FOR PERSONS INTOLERANT TO GLUTEN**
- **CODEX STAN 118 – 1979**
- **Revised 2008**
- **Gluten-free foods: gluten level does not exceed 20 ppm gluten**



GLUTEN-FREE DIET

- Omit wheat, rye, barley and triticale (a combination of wheat & rye)
- Kamut and spelt (also called farro) are also known to be harmful
- Other forms of wheat include semolina (durum wheat), farina, einkorn, bulgur, and couscous.
- Malt, a byproduct of barley, is also harmful



GLUTEN-FREE DIET

- Oats may be safe for consumption
- Oats are frequently contaminated with gluten during the harvesting and milling process, however
- Safety of oats remains questionable unless their purity can be guaranteed



TABLE 24-6 Gluten-Free Diet

Meat and meat alternates	<ul style="list-style-type: none">• <i>Recommended:</i> Fresh, frozen, salted, and smoked meats (unless processed meats contain any prohibited grains); products made with hydrolyzed vegetable protein (HVP) or hydrolyzed plant protein (HPP); eggs; dried beans and peas; tofu.• <i>Questionable:</i> Luncheon meats, sandwich spreads, meat loaf, frozen burgers, sausage, imitation meat products, meat extenders, egg substitutes, dried egg products, dry-roasted nuts, peanut butter.• <i>Avoid:</i> Products that are breaded or prepared in cream sauces, gravies.
Milk and milk products	<ul style="list-style-type: none">• <i>Recommended:</i> Milk, buttermilk, plain yogurt, cheese.• <i>Questionable:</i> Milk shakes, cheese spreads, flavored yogurt, frozen yogurt, chocolate milk.• <i>Avoid:</i> Malted milk and malted milk powders.
Breads, cereals, rice, and pasta	<ul style="list-style-type: none">• <i>Recommended:</i> Breads, baked products, and cereals made with corn, rice, soy, potato starch, potato flour, hominy, buckwheat, millet, teff, sorghum, amaranth, quinoa, arrowroot, and tapioca; pasta and noodles made with grains or starches listed above; corn tacos and corn tortillas.• <i>Questionable:</i> Oatmeal and oat bran; rice crackers, rice cakes, and corn cakes.• <i>Avoid:</i> Breads, baked products, cereals, tortillas, or pastas made with wheat, rye, barley, triticale, spelt, kamut, wheat germ, wheat bran, graham flour, durum flour, wheat starch, bulgur, farina, or semolina from wheat; commercially prepared mixes for biscuits, cornbread, muffins, pancakes, or waffles; malt and malt flavoring; pretzels; matzos.
Fruits and vegetables	<ul style="list-style-type: none">• <i>Recommended:</i> Any unprocessed fruits or vegetables.• <i>Questionable:</i> French fries, especially in fast-food restaurants; commercial salad dressings; fruit pie fillings; dried fruits.• <i>Avoid:</i> Scalloped potatoes (with wheat flour), creamed vegetables, vegetables dipped in batters.
Desserts	<ul style="list-style-type: none">• <i>Recommended:</i> Ice cream, sherbet, egg custards, or gelatin desserts that do not contain gluten; pure baking chocolate; chocolate chips; hard candy.• <i>Questionable:</i> Icing, powdered sugar, candies, chocolate bars, marshmallows.• <i>Avoid:</i> Puddings thickened with wheat flour; ice cream or sherbets that contain gluten stabilizers; baked products or doughnuts made with wheat, rye, or barley; ice cream cones; licorice.
Beverages	<ul style="list-style-type: none">• <i>Recommended:</i> Coffee; tea; cocoa; soft drinks; distilled alcoholic beverages such as rum, gin, whisky, and vodka; wine.• <i>Questionable:</i> Instant tea or coffee, coffee substitutes, chocolate drinks, hot cocoa mixes.• <i>Avoid:</i> Beer, ale, lager, malted beverages, cereal beverages (Postum), beverages that contain nondairy cream substitutes.

SOURCE: Adapted from American Dietetic Association, *Manual of Clinical Dietetics* (Chicago: American Dietetic Association, 2000), pp. 181–191.

DIABETES

- Diabetes is more common in young people with Down syndrome compared to their peers.
- Most of those with diabetes have Type 1 diabetes.
- Diabetes is diagnosed and treated according to standards set by the American Diabetes Association



DIABETES

- Key components: type 1 diabetes treatment
 - Insulin regimen –
 - Multiple daily injections or insulin pump
 - Self monitoring of blood glucose 3-4 or more times daily
 - Self-management education
 - Diet, physical activity, weight management
 - Recognizing and treating low blood sugar reactions
 - Managing diabetes during illness



DIABETES

- Successful management of diabetes
 - Consistent routine – meals, activity, blood tests, injections
 - Family support
 - Initial and ongoing education through a diabetes education program or Certified Diabetes Educator
 - Regular follow-up with primary physician and/or endocrinologist for diabetes care



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