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Heinz Infant Nutrition Institute

CELEBRATING TWENTY SIX YEARS OF INFANT NUTRITION EDUCATION

Children and Celiac Disease

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Celiac disease is an autoimmune disease that is triggered in genetically susceptible individuals by the ingestion of gluten. Gluten is the name for the storage proteins (prolamins) in wheat (gliadin), barley (hordein) and rye (secalin). In people with celiac disease, gluten ingestion causes an inflammatory reaction that damages the lining of the proximal small bowel resulting in the malabsorption of vitamins and minerals. If the disease extends into the distal small bowel there may be fat malabsorption. The only treatment for celiac disease is a strict gluten-free diet. If left untreated, celiac disease may result in serious complications including osteoporosis, lymphoma and infertility[1]. The gluten-free diet is costly and complex. In order for treatment to be successful, a dietitian with expertise in celiac disease must be consulted.

It is estimated that 1% of adults and children in the United States have celiac disease[2]. Children less than 2 years of age often present with the "classic" (gastrointestinal) symptoms which include diarrhea, abdominal distention, abdominal pain and failure to thrive. Older children may present with "atypical" (non-gastrointestinal) symptoms or no symptoms at all. Asymptomatic patients are classified as having ``silent'' or ``latent'' forms of celiac disease[3,4]. Patients with silent celiac disease have positive serum antibodies and evidence of damaged intestinal villi whereas those with latent celiac disease have positive serum antibodies, but no evidence of damaged intestinal villi. See Table 1 for a list of symptoms.

TABLE 1: SYMPTOMS OF CELIAC DISEASE IN CHILDREN [5, MODIFIED WITH PERMISSION]

Gastrointestinal Symptoms	Non-Gastrointestinal Symptoms	
Failure to Thrive	Delayed growth	Joint pain
Anorexia	Fatigue	Mouth ulcers/canker sores
Diarrhea	Irritability	Neurological symptoms
and/or constipation	Iron deficiency anemia	Edema of the hands and feet
Abdominal pain	Dental enamel defects	Dermatitis herpetiformis
Abdominal distention	Short stature	
Gas	Delayed motor development	
Vomiting	Delayed onset menarche	

Diagnosis

Early diagnosis of celiac disease helps to prevent the long term complications. However, because of the varied symptoms, the diagnosis of celiac disease may be delayed. Results from the Canadian Celiac Health Survey showed that the average delay in diagnosis from the onset of symptoms was 11.7 years[1,6]. It is recommended that celiac disease be an early consideration in the differential diagnosis of children with failure to thrive and diarrhea[7]. Serological screening may be used to assess for celiac disease. The serum IgA and the IgA antibody to human recombinant tissue transglutaminase are recommended in the initial testing for celiac disease[6]. If the antibodies are positive, an intestinal biopsy should be performed to confirm diagnosis. In a person with normal IgA, if the antibodies are negative and symptoms are present, an intestinal biopsy should be performed[8]. There must be sufficient

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gluten in the diet for the biopsy to be accurate[1]. If the diet is free of gluten, a gluten challenge must occur before the biopsy is completed. An over-the-counter, self-administered blood test for celiac disease is now available in Canada. This test is for screening purposes only and should not replace a medical diagnosis[9]. Further details on the serological screening and diagnosis can be found in the diagnosis flowchart located on the website www.celiacguide.org.

At-risk Groups

Celiac disease is associated with a number of autoimmune and non-autoimmune conditions (see Table 2). There is good evidence that certain groups (Type 1 diabetes, Down's syndrome and first degree relatives of affected individuals) should be screened for celiac disease. Those who have negative serology may subsequently develop a positive test and should be screened periodically. Gene testing is available. There is a strong association between the major histocompatibility complex class II antigens HLA-DQA1*0501-DQB1*02 (**DQ2**) and HLA-DQA1*0301-DQB1*0302 (**DQ8**) and celiac disease[7]. Environmental factors such as surgery or infection may trigger the onset of symptoms[1].

Nutrition Assessment

Treatment for celiac disease involves a lifelong gluten-free diet. A dietitian with expertise in celiac disease is necessary for nutrition assessment, education and follow-up. Initially, a thorough assessment of dietary intake should be conducted to assess typical eating habits and adequacy of nutrient intake. See Table 3 for nutrition assessment checklist.

Treatment and Follow-Up

Once the initial assessment is complete, the dietitian may tailor recommendations to specific needs and deficiencies as well as educate on the gluten-free diet. See Table 4 for an education checklist.

For more information on assessment and nutritional complications of celiac disease refer to www.celiacguide.org.

Regular follow-up with a gastroenterologist is recommended. Studies show that children's adherence to the gluten-free diet ranges between 45%- 90%[1,7]. After 6 to 12 months of maintaining a strict gluten-free diet, symptoms should disappear, serological tests should return to normal and the small intestine should heal. Serological tests should be monitored over time to assess compliance.

Most children newly diagnosed with celiac disease tolerate lactose and do not require a lactose-free diet. However, children with severe disease may benefit from a temporary lactose restriction[6].

Gluten-free foods may be low in fibre, iron, folate and B vitamins. Children should be monitored for growth (BMI, height and weight) and relevant laboratory measures (see Table 3). A gluten-free children's complete multivitamin is recommended.

Food Labels and Ingredients

The gluten-free diet must be free of all wheat, rye, barley (includes malt) and contaminated oats (see section on oats). In Canada, if the term "gluten-free" is on a food label, it means that there is less than 20 ppm of gluten. The Canadian Food Inspection Agency (CFIA) conducts periodic testing of foods using an ELISA test which has an analytical limitation of 20 ppm. Health Canada and the CFIA have developed proposed regulatory amendments to the Food and Drug Regulations

TABLE 2: AT-RISK GROUPS[2,7]

Individuals with:	
Autoimmune hepatitis	Turner syndrome
Rheumatoid arthritis	Type 1 diabetes
Lupus	Thyroiditis
Selective IgA deficiency	Unexplained liver enzyme elevation
Williams syndrome	Down's syndrome
Ataxia	Peripheral neuropathy

TABLE 3: NUTRITION ASSESSMENT CHECKLIST

DIET HISTORY ASSESSMENT OF:
Calories
Protein
Calcium
Iron
B vitamins
Fibre
Vitamin D
Review of eating patterns and food preferences
Willingness and ability to cook and prepare foods
Eating away from the home
Nutritional or herbal supplements and vitamins
MEDICAL REVIEW OF:
Medications
Symptoms
Family history of celiac disease
Height, weight, Body Mass Index (BMI), Growth pattern
Stool pattern
REVIEW OF RELEVANT TESTS:
Relevant bloodwork (albumin, fat soluble vitamins, CBC, ferritin, folate, vitamin B12, vitamin B6, calcium, PTH, anti-tissue transglutaminase antibody levels, IgA)
Endoscopy report
Bone mineral density

TABLE 4: EDUCATION CHECKLIST

Review of food label reading and ingredient lists (see Table 5 for ingredient list)
Menu planning (ideas for school lunches, travel packs, snacks, kid-friendly brands)
Baking (flour substitutions, cookbooks, recipes)
Nutrients (protein, fibre, calcium, iron, folate, vitamin D)
Review of food companies that produce gluten-free foods
Review of shopping ideas (where to purchase gluten-free foods)
Budgeting (ideas on how to purchase gluten-free foods while on a budget)
Cross-contamination (see paragraph on cross-contamination)
Oats (see paragraph on oats)
Eating away from the home (travel, parties, university, restaurants, cafeterias, potlucks)
Vitamin and mineral supplements (these must be gluten-free)
Medications (these must be gluten-free; www.glutenfreedrugs.com)

called Enhanced Labeling For Food Allergen and Gluten Sources and Added Sulphites (http://www.hc-sc.gc.ca/fn-an/label-etiquet/allergen/index-eng.php). These regulations have not yet been passed. At present, food labels must list all top allergens (Food Allergen Labeling and Consumer Protection Act, 2004). This includes wheat, but does not include barley, rye or oats. It is imperative that people with celiac disease be educated on how to read and understand ingredient lists. Foods labeled "gluten-free" are safe. The ingredients in all foods without the gluten-free label must be reviewed carefully. *Pocket Dictionary: Acceptablility of Foods and Food Ingredients for the Gluten-Free Diet* from the Canadian Celiac Association (www.celiac.ca) is an invaluable resource. This book lists all ingredients that are allowed, not allowed and ingredients to check. Table 5 provides a list of safe and toxic grains as well as hidden gluten sources. Gluten is often a "hidden" ingredient in foods as well as medications and vitamins.

Planning a Nutritious Gluten-free Diet

The gluten-free diet should be varied and nutritious. There are many foods which are naturally gluten-free and can be encouraged in the initial stages of the transition from a regular diet to a gluten-free diet.

There are gluten-free replacements for breads, cereals, pasta, muffins, cakes, pies and cookies. Gluten-free replacement foods are often lower in fibre and higher in sugar, fat and calories. This may affect stool patterns, weight control and cholesterol levels. Gluten-free foods are not consistently fortified and may not provide sufficient amounts of certain nutrients (fibre, iron, calcium and the B vitamins)[10,11]. There are gluten-free fortified infant cereals available. The dietitian should encourage gluten-free whole grains (See Table 5) and foods rich in iron, folate, B vitamins and fibre.

Gluten-free foods are expensive and the dietitian must consider this in the initial assessment and teaching. The dietitian should provide guidance on where to buy foods locally. Health food stores, gourmet type grocery stores and some grocery store chains contain a variety of gluten-free foods. In grocery stores the gluten-free foods are often found in the organic or natural food sections. Gluten-free foods can also be ordered online but the cost is higher because of shipping fees.

Safe foods:

- Fruits and vegetables (in their natural state)
- Meat, poultry, eggs, nuts, legumes (in their natural state)
- Nut butters
- Milk, most plain or fruit yogurt (with no granola), cheese, ice cream/pudding (with no cookies or brownies)
- Safe grains (see table 5)
- Other foods- Sugar, artificial sweeteners, pure chocolate, mayonnaise, oil, butter, margarine, spices and some condiments (olives, pickles, plain mustard, ketchup, jam, jelly, syrup, all vinegar except malt vinegar)
- Beverages- Fruit juices, fruit drinks, coffee, tea, soda, iced tea, all alcohol (except beer)

Cross-Contamination

Gluten-free foods must be kept gluten-free. Cross-contamination prevention procedures are required. All food preparation areas, utensils, pots, pans, plates, cutlery and cooking appliances must be well-cleaned. It is recommended there be separate toasters, colanders and condiments such as peanut butter, butter, etc. Buffets and bulk bins should be avoided. Foods that have been deep fried in the same oil as breaded products (e.g. French fries, wings, nachos, etc.) should be avoided.

Oats

Health Canada and the Canadian Celiac Association agree that the majority of people with celiac disease can tolerate moderate amounts of pure oats (uncontaminated with other cereal grains such as wheat, barley and rye). Pure oats are an

TABLE 5: SAFE AND UNSAFE GRAINS AND FOODS

Safe Grains		Toxic Grains	Hidden Gluten Sources	
***Amaranth**	***Popcorn**	Barley (includes: malt)	Smarties®	Lipstick
Arrowroot	*Potato	Bulgar	Pringles®	Vitamins
*Bean flours	Potato flour, potato starch	Coucous	Pretzels	Artificial seafood
***Buckwheat**	***Quinoa**	Durum	Licorice	Gravy
Cassava	Rice (flour, ***brown rice**, white rice, ***wild rice, *rice bran**)	Einkhorn	Communion wafer	Sauces
*Chickpea flour		Emmer	Matzo	Salad dressings
Coconut flour		Farina	Cake frosting	Soups
Corn	***Sorghum**	Faro	Worcestershire sauce	Meatballs
Corn grits, cornmeal, corn flour, cornstarch, corn bran,	Soy (flour, soybean)	Flour	Broth	Sausage
	Tapioca (pearls, flour, starch)	Graham flour	Medications (see www.glutenfreedrugs.com)	Hamburger patties
*corn on the cob		Kamut		Restaurant French fries
*Flax seed	***Teff**	Matzo	Herbal supplements	Rice pilaf
*Mesquite flour	*Yams	Malt	Soy sauce	
***Millet**	Yucca	Rye	Playdough	
*Montina flour		Semolina	Rice Krispies®	
Nut flours		Spelt	Corn flakes	
***Oats** (pure, uncontaminated)		Triticale	Malt vinegar	
		Wheat	Beer	

Items with a * contain more micronutrients and fibre.

Bolded items are whole grains (50% of grains should be whole grains; http://www.hc-sc.gc.ca/fn-an/alt_formats/hpfb-dgpsa/pdf/food-guide-aliment/view_eatwell_vue_bienmang-eng.pdf)

important source of nutrients including fibre, protein and iron. It is recommended that oats be introduced under medical supervision. In children, the amounts of pure oats should be limited to 20-25 grams/day (65 ml or 1/4 cup dry rolled oats) and 50 -70 grams/day (125 to 175 ml or 1/2 to 3/4 cup dry rolled oats) in adults. For more information on oats as part of the gluten-free diet refer to the Canadian Celiac Association's Position statements on oats www.celiac.ca as well as as well as Health Canada's Position on the Introduction of Oats to the Diet of Individuals Diagnosed with Celiac Disease (www.hc-sc.gc.ca/fn-an/securit/allerg/cel-coe/oats_cd-avoine-eng.php). Most commercial oats are contaminated with gluten; however, pure uncontaminated oats are available from the following companies:

www.creamhillestates.com
www.glutenfreeoats.com
www.bobsredmill.com
www.onlyoats.com
www.giftsofnature.net

Eating Away from Home

It is recommended that the parents of a child with celiac disease speak with the school (teacher and principal) about the necessity of the gluten-free diet. Teachers will need to be made aware of safe foods and beverages. Most families find it easier to send a packed school lunch. It is helpful to provide the school with some gluten-free treats for school parties. When children are attending sleepovers or birthday parties, parents should try to provide gluten-free foods that look similar to what the other children will be eating. Adolescents should be advised on how to navigate social situations while maintaining a gluten-free diet (snacks, pizza replacements, gluten-free beer, alcohol). Preparation should be provided for travel, college and eating in restaurants. The Canadian Celiac Association (www.celiac.ca) is an excellent resource for ongoing support and education. The Gluten-free Restaurant Awareness Program is a program available in the United States through the Gluten Intolerance Group. The program has started to be implemented in Toronto, Canada with the intention of spreading throughout the rest of the country.

Restaurant websites:
www.glutenfreerestaurants.org
www.glutenfreeonthego.com
www.triumphdining.com

Travel websites:
www.glutenfreeonthego.com
www.selectwisely.com

Recommended Websites:
www.celiacguide.org
www.dietitians.ca
(PEN pathway on celiac disease)
www.celiaccentral.org
www.celiac.ca
www.glutenfreediet.ca
www.celiacdiseasecenter.org
www.celiac.org

Summary/ Key Points

1. Successful treatment of celiac disease requires a registered dietitian with expertise in celiac disease.
2. Thorough assessment, education and follow-up are recommended.
3. The gluten-free diet should be rich in gluten-free whole grains, fruits and vegetables and fortified foods.
4. Children need to be followed for growth, celiac antibodies and other relevant blood levels.

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11. Hallert C, Grant C, Green S, et al. Evidence of poor vitamin status in coeliac patients on a gluten-free diet for 10 years. *Aliment Pharmacol Ther* 2002;16:1333-1339
12. Case, Shelley. *Gluten-Free Diet A Comprehensive Resource Guide*. Revised Expanded Edition. Publisher: Case Nutrition Consulting Inc. 2008

Recommended Books
(Titles and Authors Provided)

The Gluten-Free Nutrition Guide
Tricia Thompson, 2008
ISBN 978-0-07-154541-9

The Gluten-Free Diet
A comprehensive resource guide-revised and expanded version.
Shelley Case, 2008
ISBN 978-1-897010-54-9

Celiac Disease-
A Hidden Epidemic
Dr. Peter Green and Rory Jones, 2006
ISBN -10:0-06-076693-X

Canadian Celiac Association
Pocket Dictionary, 2006
ISBN 0-921026-21-8
www.celiac.ca

Children's Books[12, with permission]

Raising Your Celiac Child:
Guidelines for a Gluten-Free Life
DVD
www.childrenshospital.org/celiac

Kids with Celiac Disease:
A Family Guide to Raising Happy, Healthy, Gluten-Free Children by Danna Korn
ISBN 1-89062-72-16

Gluten-Free Friends: An Activity Book for Kids by Nancy Patin Falini
ISBN 1-889374-09-1

No More Cupcakes & Tummy Aches:
A Story for Parents and Their Celiac Children to Share by Jax Peters Lowell
ISBN 1-4134-6255-3

Nothing Beats Gluten-free Cooking by the Celiac Disease Center at Columbia University
ISBN 0-9742370-0-0

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DIETARY GUIDANCE FOR INDIVIDUALS WITH CELIAC DISEASE

SAFE FOODS

Fruits and vegetables (in their natural state)

Meat, poultry, eggs, nuts, legumes (in their natural state)

Nut butters

Milk, most plain or fruit yogurt (with no granola), cheese, ice cream/pudding (with no cookies or brownies)

Safe grains (see below)

Other foods- Sugar, artificial sweeteners, pure chocolate, mayonnaise, oil, butter, margarine, spices and some condiments (olives, pickles, plain mustard, ketchup, jam, jelly, syrup, all vinegar except malt vinegar)

Beverages- Fruit juices, fruit drinks, coffee, tea, soda, iced tea, all alcohol (except beer)

SAFE GRAINS AND FOODS

***Amaranth**
Arrowroot
*Bean flours
***Buckwheat**
Cassava
*Chickpea flour
Coconut flour
Corn
Corn grits, cornmeal, corn flour, cornstarch, corn bran, *corn on the cob
*Flax seed
*Mesquite flour
***Millet**
*Montina flour
Nut flours
***Oats** (pure, uncontaminated)
***Popcorn**
*Potato
Potato flour, potato starch
***Quinoa**
Rice (flour, ***brown rice**, white rice, ***wild rice**, ***rice bran**)
***Sorghum**
Soy (flour, soybean)
Tapioca (pearls, flour, starch)
***Teff**
*Yams
Yucca

TOXIC GRAINS AND FOODS

Barley (includes: malt)
Bulgar
Coucous
Durum
Einkhorn
Emmer
Farina
Faro
Flour
Graham flour
Kamut
Matzo
Rye
Semolina
Spelt
Triticale
Wheat

HIDDEN GLUTEN SOURCES

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Rice Krispies®
Corn flakes
Malt vinegar
Beer
Lipstick
Vitamins
Artificial seafood
Gravy
Sauces
Salad dressings
Soups
Meatballs
Sausages
Hamburger patties
Restaurant French fries
Rice Pilaf

With compliments of:

Items with a * contain more micronutrients and fibre.
Bolded items are whole grains (50% of grains should be whole grains; http://www.hc-sc.gc.ca/fn-an/alt_formats/hpfb-dgpsa/pdf/food-guide-aliment/view_eatwell_vue_bienmang-eng.pdf)

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