

The Gluten-Free Diet: How to Provide Effective Education and Resources

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A strict gluten-free diet (GFD) for life is the only treatment for celiac disease (CD). This article reviews (1) the impact of the GFD on the quality of life of individuals with CD and their families; (2) the causes of poorly controlled CD; (3) the access to and source and quality of information provided by health professionals and other groups; (4) management strategies, including nutritional assessment and education guidelines; (5) a variety of resources available to individuals and health professionals; (6) innovative educational initiatives and partnerships; and (7) specific recommendations to address the increasing numbers of people with CD and the growing need for gluten-free (GF) foods and further education about CD and the GFD. Successful management of CD requires a team approach, including the person with CD and his or her family, physician, dietitian, and celiac support group; an individualized approach; understanding of quality of life issues; use of evidence-based, current information and resources; and regular follow-up to monitor compliance, nutritional status, and additional information and support. The physician must clearly communicate, with a positive attitude, an overview of CD and strongly emphasize the importance of a GFD for life. It is essential that the physician initiate an immediate referral to a dietitian with expertise in CD for nutritional assessment, diet education, meal planning, and assistance with the adaptation to the challenging new gluten-free lifestyle. Good dietary compliance will reduce the risk of further complications and associated health care costs and improve quality of life in patients with CD.

A strict gluten-free diet (GFD) for life is the only treatment for celiac disease (CD). Changing lifelong eating habits and adapting to the new gluten-free (GF) lifestyle can be a huge challenge for most people with CD for a variety of reasons. Wheat and wheat-based products are major staples in the North American diet (Table 1). Also, hectic lifestyles have resulted in more meals eaten away from home and reliance on packaged, convenience foods, which often contain wheat. Another major challenge is that gluten is a hidden ingredient in many foods. American and Canadian labeling regulations do not re-

quire manufacturers to declare all components of ingredients on the food label (eg, seasonings, flavorings, modified food starch). People with CD may be unaware of these exceptions, as well as other foods that contain gluten and terms used to denote gluten (Table 2). In addition, the cost of GF specialty foods is significantly higher than gluten-containing foods, and obtaining these specialty foods is difficult for some patients.

Many studies have investigated the impact of celiac disease and following a GFD on the quality of life in adults¹⁻⁵ and children,^{6,7} with varying results. In addition, several studies have looked at specific lifestyle issues and their effect on the patient's ability to follow the GFD in adults^{3,8-11} and children with CD.¹² A US survey of 253 adult patients (range, 18-55 years; 74% female) revealed that adhering to a GFD negatively impacted the ability to eat out (86%), traveling (82%), family life (67%), and work/career (41%).¹¹ The Canadian Celiac Association Health Survey of 2618 adults and 168 children with biopsy-confirmed CD identified a number of concerns.^{9,12} Forty-four percent of adults found the GFD very or moderately difficult to follow. Determining whether foods were GF (85%), finding GF food (85%), and finding good quality GF foods (83%) all or some of the time were major issues. Also, 79% avoided restaurants, 38% avoided traveling, and 94% brought GF food while traveling all or some of the time. The children and their families had difficulty determining whether foods were GF (92%) and finding GF foods (90%), as well as avoiding restaurants (95%) and traveling (46%) all or some of the time. Children with CD were angry about having to follow a special diet (72%), felt different from other children (69%), were left out of activities at school or friends' homes (61%), and were embarrassed to bring GF foods to parties (53%) all or some of the time. Green et al³ conducted a National Survey of 1612 adults (ages

Abbreviations used in this paper: CD, celiac disease; GF, gluten free; GFD, gluten-free diet; IOM, Institute of Medicine.

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Table 1. Common Wheat-Based Foods in the North American Diet

Breakfast items
Cold and hot cereals
Toast
Muffins
Bagels
Pancakes, waffles, french toast
Lunch items
Sandwiches, wraps
Hot dogs
Macaroni and cheese
Pizza
Soup and crackers
Cookies, granola bars, cake, and pastries
Fast foods
Pizza
Hot dogs and hamburgers
Chicken nuggets
Pasta
Fish and chips
Sub sandwiches, wraps
Snack foods
Cookies
Crackers
Snack bars
Pretzels
Chocolate bars
Licorice
Seasoned potato and nacho chips (Seasonings often contain wheat starch or flour as a carrier agent)

18–92 years) and found that dietary lapses occurred in restaurants (26%) and at parties and social functions (21%).

For effective counseling of individuals with CD, physicians and dietitians must understand the emotional and psychologic impact of the disease and diet, as well as the complex quality of life issues patients and their families face on a daily basis, and offer practical advice and specific strategies to help them successfully follow the GFD.^{8,9,11}

Sources and Quality of Information

Patients seek information on CD and the GFD from a variety of sources, including health professionals; celiac support groups; food companies; health food and grocery stores; alternative health practitioners; the Internet; libraries; medical, dietetic, and nursing associations; government departments; media; family; and friends. Unfortunately, patients frequently receive outdated, inaccurate, and/or conflicting information from many of these sources. This results in confused and frustrated patients, who unnecessarily restrict certain foods, thus limiting the variety and nutritional quality of their diet.

Several surveys have ascertained where patients obtain information about CD and the GFD and their perceived

quality of information from these sources.^{3,8–11,13} In the US survey of 253 adults with CD, 71% found information on the GFD from books, support groups, family, friends, and the Internet compared with 17% from physicians and 13% from dietitians.³ Of those who saw a dietitian, only 21% rated the information helpful. Respondents in the Canadian Celiac Health Survey thought that excellent information on CD and the GFD was

Table 2. Gluten-Containing Ingredients and Questionable Products

Gluten-containing grains, starches, and flours^a
Barley
Bulgur
Cereal binding
Couscous ^b
Durum ^b
Einkorn ^b
Emmer ^b
Farro ^b
Graham flour
Kamut ^b
Malt, ^c malt extract, ^c malt flavoring, ^c malt syrup ^c
Oats, ^d oat bran, ^d oat syrup ^d
Rye
Semolina ^b
Spelt ^b
Triticale
Wheat, wheat bran, wheat germ, wheat starch
Frequently overlooked foods that often contain gluten^e
Baked beans
Breeding
Chocolate bars
Communion wafers
Croutons
Dry roasted nuts
Gravy
Icings and frostings
Imitation bacon bits
Imitation seafood
Licorice
Marinades
Meat loaf
Pastas
Processed meats and poultry
Roux
Salad dressings
Sauces
Sausage products
Seasonings
Self-basting poultry
Soups, soup bases, broth, bouillon cubes
Soy sauce
Stuffings
Thickeners

^aFrom: Case S. *Gluten-Free Diet: A Comprehensive Resource Guide*, 2004, Case Nutrition Consulting, Regina, SK., Canada.

^bTypes of wheat.

^cDerived from barley.

^dOats are not recommended by celiac groups in North America due to cross contamination with wheat or barley.

^eAdapted from: *Quick Start Diet Guidelines*, Celiac Disease Foundation and Gluten Intolerance Group of North America, 2004.

provided by the Canadian Celiac Association (64%), another CD patient (59%), gastroenterologist (28%), dietitian (26%), the Internet (22%), and family physician (12%).⁹ In another Canadian survey of 234 people from the Quebec Celiac Foundation, 44% received a large quantity of information from the dietitian, but only 57% had a high level of confidence in the information received.¹⁰ Green et al surveyed 1612 adults with CD and found that 66% were referred to a dietitian; however, 88% claimed that the majority of most useful information came from the celiac support groups and not the dietitian.³ A 2001 study of the attitudes of 160 people with CD toward dietitians and medical nutrition therapy (MNT) revealed that, although 73% had been referred to a dietitian, 54% did not find the dietitian knowledgeable about CD or helpful (53%).¹³

The Canadian Celiac Health Survey⁹ and two US National Celiac Surveys^{3,14} revealed that many physicians were unaware of CD, resulting in significant delays in diagnosis and/or misdiagnoses. Also, national celiac organizations have expressed other concerns about physician practices, including recommending a trial GFD before the serology and biopsy have been completed which can interfere with making a correct diagnosis, not emphasizing the importance of a strict GFD for life, and using outdated information and resources.

Until recently, CD was considered a rare disorder, and most physicians and dietitians have received minimal education regarding CD and the GFD at both the undergraduate and practicing levels. This underscores the need for additional training in CD and the GFD if physicians and dietitians are to manage effectively the treatment of people with CD.

Access to Information

Because nutrition therapy is the only treatment for celiac disease, it is essential that newly diagnosed patients be referred to a dietitian with expertise in CD. Case (2004 unpublished) conducted an on-line and/or telephone survey of 102 dietitians in the United States (45) and Canada (47) to ascertain referral procedures and practices. CD is considered a high priority by the majority of the dietitians, with patients being seen within 1–2 weeks of referral in both the United States and Canada. Unfortunately, many patients are not being referred to a dietitian. Another major concern in the United States is the limited or lack of reimbursement for nutrition therapy and education by insurance companies. Most patients must pay for the service, which can range from \$60 to \$295/hour, with an average rate of \$92/hour. Some patients are unwilling or unable to afford the

counseling and report seeking alternative sources of information.

The average initial visit ranged from 60 to 90 minutes, with the follow-up session (in person or telephone) ranging between 30 and 60 minutes. However, not all patients were seen for follow-up for several reasons; patients were unwilling to return because of limited time or long traveling distance to the dietitian's office, lack of reimbursement, and/or they felt further education on the diet was unnecessary.

Successful Management and Effective Education

Successful management of CD requires (1) a team approach, including the person with CD, family, physicians, dietitian, celiac support group, and caregivers; (2) an individualized approach; (3) an understanding of quality of life issues; (4) use of evidence-based, current information and resources; and (5) regular follow-up to monitor compliance and nutritional status, as well as additional information and support.^{15,16}

Once a diagnosis is made, the physician must clearly communicate, with a positive and optimistic attitude, an overview of CD and strongly emphasize the importance of a strict GFD diet for life.¹⁶ It is essential that the physician initiate an immediate referral to a dietitian with expertise in CD for nutritional assessment, diet education, meal planning, and assistance with the social and emotional adaptation to the new GF lifestyle.^{16–20} A delay in referral, or no referral at all, increases the likelihood of the patient obtaining inaccurate information from the Internet, health food stores, alternative health practitioners, family, friends, and other sources, often resulting in confusion, frustration, and insufficient knowledge regarding CD and the GFD.²⁰

The dietitian is the most qualified health care professional to provide nutrition therapy. Dietitians have extensive academic and practical experience including (1) in-depth knowledge regarding the role of food and nutrition in the prevention, treatment, and progression of acute and chronic disease and how disease and treatment affect food and nutritional needs; (2) nutrition composition and food preparation information; (3) socioeconomic, psychologic, and educational factors that affect food and nutrition behavior of people across their lifespan; (4) skills to translate scientific information into laymen's terms and assist individuals in gaining knowledge, self-understanding, improved decision making, and behavioral changes. Although other health care professionals can disseminate nutrition advice, they do not have the training in nutrition sciences and food compo-

Table 3. Nutrition Assessment and Education For Celiac Disease**Complete nutritional assessment**

Anthropometrics: Ht., Wt., BMI, pediatric growth charts, skin, hair, nails
 Tests/labs: Celiac antibody and endoscopy results, bone density results, Hgb, Hct, iron, transferrin, ferritin, TIBC, B₁₂, folate, albumin, chol, HDL, LDL, sodium, potassium, calcium, other tests (eg, hydrogen breath test)
 Symptoms review: Abdominal pain, bloating, gas, diarrhea, constipation, fatigue, bone/joint pain, mouth ulcers, depression, other
 Medical: Associated symptoms or related illnesses (eg, lactose intolerance, osteopenia, osteoporosis, anemia, diabetes, other food intolerances), medications, supplements, herbs, alternative therapies, family history of celiac related symptoms
 Diet Hx./Food Record: Nutrient Composition (look for adequate Kcal, protein, B complex, vitamin D, calcium, iron, fiber)
 Lifestyle issues (shopping and food preparation issues, cooking experience, willingness and time to cook, use of convenience foods, food preferences, eating away from home (eg, restaurants, school, work), financial determinants, and ethnic and religious belief considerations
 Social/Emotional Assessment: Query response to diagnosis and diet, knowledge, readiness to learn, motivation, family support, literacy level

Education

Explanation of celiac disease, definition and role of gluten
 Gluten-free diet instruction: Grains and flours to avoid and those allowed
 Variety of foods allowed, meal planning guidelines, nutritionally balanced eating
 Nutritional issues (eg, iron, calcium, vitamin D, B vitamins, fiber, enrichment)
 Nutrition supplements as needed
 Shopping, label reading, cross contamination issues, recipes, substitutions, how to use GF grains
 Eating out, travel, how to deal with family and friends
 List of manufacturers of GF foods and local stores that carry GF foods
 Resources: Books, cookbooks, newsletters, magazines, Web sites, celiac support group contact information (local and national)

Follow-up

Encourage patient to return for regular follow-up for assessment, modifications to treatment plan, and further information
 Schedule appointments based on patient's need and/or interest
 Instruct patient to call with questions or concerns
 Communicate pertinent information to physicians

NOTE. Adapted from Anne Lee, RD, Celiac Disease Center at Columbia University in ADA Clinical Connections, 2003.¹⁹

sition to be able to translate complex medical nutrition concepts and issues into attainable dietary changes. **Table 3** presents a summary of the nutritional assessment, education, and follow-up of newly diagnosed individuals with CD.

The physician and dietitian should also encourage the patient to join a local and/or national CD patient group for ongoing support because patients who are active members are usually more knowledgeable and compliant with their diet.¹⁶ **Table 4** contains a listing of national celiac organizations in the United States and Canada.

Poorly Controlled/Nonresponsive Celiac Disease

It is critical to conduct a systematic review of nonresponsive CD because several factors may be responsible for poor control such as intentional and/or unintentional gluten ingestion and coexisting gastrointestinal conditions (eg, lactose intolerance, bacterial overgrowth, microscopic colitis, pancreatic insufficiency, collagenous colitis, enteropathy-associated T-cell lymphoma, and refractory sprue).^{15,18,21,22} The most common cause of non-responsive CD is gluten ingestion, either intentional or unintentional.^{1,18,21,23} In a recent study, 51% of patients (25 of 49) continued to have symptoms because of inad-

vertent gluten ingestion.²¹ Most common causes were a result of eating out or consuming corn or rice cereals with barley malt flavoring. Although most patients had been given advice regarding the GFD and the majority belonged to a CD support group, many received outdated information regarding the diet and unknowingly ate gluten-containing foods. The authors emphasized the

Table 4. National Celiac Organizations

Celiac Disease Foundation (CDF)
 13251 Ventura Blvd., Suite #1
 Studio City, CA 91604-1838
 Ph. 818-990-2354
www.celiac.org
 Celiac Sprue Association/USA, Inc. (CSA)
 P.O. Box 31700
 Omaha, NE 68131
 Ph. 877-272-4272
www.csaceliacs.org
 Gluten Intolerance Group of North America (GIG)
 15110 10th Ave. SW, Suite A
 Seattle, WA 98166-1820
 Ph. 206-246-6652
www.gluten.net
 Canadian Celiac Association (CCA)
 5170 Dixie Road, Suite 204
 Mississauga, ON L4W 1E3 Canada
 Ph. 905-507-6208
www.celiac.ca

Table 5. Celiac Disease and Gluten-Free Diet Resources**Books: Diet and Disease**

- Gluten-Free Diet: A Comprehensive Resource Guide, 2004 Edition
Shelley Case, BSc, RD
www.glutenfreediet.ca
- Celiac Disease Nutrition Guide
Tricia Thompson, MS, RD, and Meri Lou Dobbler, RD
www.eatright.org
- Kids with Celiac Disease: A Family Guide to Raising Happy,
Healthy Gluten-Free Children
Danna Korn
www.woodbinehouse.com
- Gluten-Free Friends: An Activity Book for Kids
Nancy Patin-Falini, MA, RD, LDN
www.savorypalate.com
- Eating Gluten-Free with Emily: A Story for Children with Celiac
Disease
Bonnie Kruszka
www.woodbinehouse.com
- What? No Wheat? A Lighthearted Primer to Living the Gluten-
Free, Wheat-Free Life
LynnRae Ries
www.whatnowheat.com

Books: Diabetes and Celiac Disease

- Managing Diabetes and Celiac Disease . . . Together
Canadian Celiac Association
www.celiac.ca
- Diabetes, Celiac Disease and Me: An Introduction to Living with
Both Diseases
Gluten Intolerance Group
www.gluten.net

Magazines and Newsletters

- Gluten-Free Living Magazine
www.glutenfreeliving.com
- Living Without Magazine
www.livingwithout.com

Cookbooks and Cooking Resources

- The Gluten-Free Gourmet Cooks Comfort Foods
The Gluten-Free Gourmet—Living Well Without Wheat
More from the Gluten-FreeGourmet
The Gluten-Free Gourmet Cooks Fast and Healthy
The Gluten-Free Gourmet Bakes Bread
The Gluten-Free Gourmet Makes Dessert
Bette Hagman
- Gluten-Free 101: Easy Basic Dishes Without Wheat
Wheat-Free Recipes and Menus: Delicious Healthful Eating for
People with Food Sensitivities
Special Diet Solutions: Healthy Cooking Without Wheat, Gluten,
Dairy, Eggs, Yeast, or Refined Sugar
Gluten-Free Celebrations: Memorable Meals Without Wheat
Carol Fenster, PhD
www.savorypalate.com
- Wheat-Free, Gluten-Free Recipes for Special Diets
Wheat-Free, Gluten-Free Cookbook for Kids and Working Adults
Wheat-Free, Gluten-Free Dessert Cookbook
Wheat-Free, Gluten-Free Reduced Calorie Cookbook
Connie Sarros
www.gfbooks.homestead.com
- 125 Best Gluten-Free Recipes
The Best Gluten-Free Family Cookbook
Donna Washburn, P.H.Ec. and Heather Butt, P.H.Ec.
www.bestbreadrecipes.com

Table 5. continued

- Cooking Gluten-Free- A Food Lover's Collection of Chef and Family
Recipes Without Gluten or Wheat
Karen Robertson
www.cookingglutenfree.com
- Nothing Beats Gluten-Free Cooking: A Children's Cookbook
Celiac Disease Center at Columbia University
www.celiacdiseasecenter.columbia.edu
- Gluten-Free Baking
Rebecca Reilly
www.mysimon.com
- Glutenfreeda
On-line cooking site and cooking school
www.glutenfreeda.com

Travel and Dining Resources

- Bob and Ruth's Dining and Travel Club
www.bobandruths.com
- Waiter, Is There Wheat In My Soup? The Official Guide to Dining
Out, Shopping, and Traveling Gluten-Free and Allergen-Free
LynnRae Ries
www.whatnowheat.com

Miscellaneous Resources

- Quick Start Diet Guidelines Pamphlet
Celiac Disease Foundation and Gluten Intolerance Group of North
America
www.gluten.net
www.celiac.org
- Pocket Dictionary: Acceptability of Foods and Food Ingredients for
the Gluten-Free Diet
Canadian Celiac Association
www.celiac.ca
- Going Gluten-Free: A Primer for Clinicians
Melinda Dennis, MS, RD, LDN, and Shelley Case, BSc, RD
Practical Gastroenterol 2004;28:86–104.
- Medline Plus: Celiac Disease Section
www.nlm.nih.gov/medlineplus/celiacdisease.html
- Steve Plogsted's Medication List
www.glutenfreedugs.com
- Cel-Pro
Celiac listserv for health professionals
Send email to mjones@digital.net with name and professional
interest in celiac disease
- Dietitians in Gluten Intolerance Disease (DIGID)
Sub-unit of Medical Nutrition Practice Group, American Dietetic
Association (ADA)
Must be a member of ADA and the practice group. Call 800-877-
1600, ext. 5000 for more information.

importance of ongoing follow-up and education with a dietitian experienced in CD. Better dietary compliance can reduce the risk of further complications and associated health care costs and improve the quality of life of patients with CD.

Resources

There are many resources on CD and the GFD available to patients/families and health professionals from a wide variety of sources (Table 5). It is important

that they choose resources that are current and evidence-based. This is a major challenge because research and information on CD and the GFD is ongoing and continually expanding.

Positive Initiatives

Innovative initiatives and partnerships among health professionals, CD patient groups, GF specialty companies, and health food and grocery stores have been established to raise awareness about the increasing number of people with CD, the growing need for GF foods, and the further education and training regarding CD and the GFD. The following are examples of specific initiatives.

Dietitian Projects

- American and Canadian dietitians specializing in CD were joint authors of the CD section in the Manual of Clinical Dietetics, 6th edition, by the American Dietetic Association and Dietitians of Canada.
- Dietitians in Gluten Intolerance Diseases (DIGID), a specialty subunit of the American Dietetic Association (ADA) Medical Nutrition Practice Group, was established to provide education, resources, and a list serve.
- A number of articles on CD and the GFD were written for many journals, magazines, and ADA dietetic practice groups in the last 2 years.
- At the last 3 ADA annual conferences, CD and GFD educational sessions and displays were featured. In addition, GF specialty companies and dietitians have joined together to showcase GF products and resources in a specially designated area of the main exhibit hall.

Quick Start Diet Guidelines

The Celiac Disease Foundation and Gluten Intolerance Group of North America developed an educational brochure to assist dietitians and their patients on how to get started on the GFD. It has been widely distributed to many different groups and patients throughout the United States.

“Celiac Disease: Hidden and Dangerous Workshops”

Dietitian advisors with the Canadian Celiac Association and the Dietitians of Canada have worked together to offer 3-hour comprehensive workshops for dietitians on the presentation, diagnosis, and management of CD. These have been presented by 3 celiac

specialist dietitians from the CCA Professional Advisory Board in 13 major Canadian cities, as well as 1 teleconference to 25 smaller cities over the past 2 years, with excellent attendance and feedback.

American Celiac Task Force

Celiac Research and Education Centers, CD support organizations, GF food companies, and others have formed this task force to lobby Congress for improved food-labeling regulations.

Grocery Stores and Dietitians

- Several American and Canadian grocery store chains employ dietitians who have recently begun offering GFD educational sessions and cooking classes in the store.
- Wegmans Food Market stores have developed “wellness keys” for specific health claims, including GF for all their Wegman’s brand products. Consumers are able to determine the GF status of all these products using the labeling key.

Health Food Stores, GF Specialty Companies, and Dietitians

Health food stores, GF specialty companies, and dietitians have worked together to offer GFD educational sessions, cooking classes, and product sampling.

Finnish KIHO Project

The Finnish Coeliac Society developed a National Treatment Model of Coeliac Disease and offered a nationwide training program (1-day course) for physicians, dietitians, nurses, and other health care personnel. Twenty-two courses were conducted over 2 years by celiac specialists.

Recommendations

1. Additional training on CD and its dietary treatment at the undergraduate, internship/residency, and practicing levels for physicians, dietitians, nurses, and other allied health professionals is essential.
2. Dietetic and Medical Associations need to establish specific Medical Nutrition Therapy protocols and offer continuing professional education (CPE) programs at national and regional conferences, as well as practical on-line and print resources.
3. It is essential that dietitians providing Medical Nutrition Therapy for CD be covered by insurance for initial and follow-up nutrition management and education. The Institute of Medicine (IOM)

has identified registered dietitians as the single identifiable group of health professionals with standardized education, clinical training, continuing education, and national credentialing requirements necessary to be directly reimbursed as a provider of nutrition therapy.²⁴

4. Enhanced and more comprehensive food-labeling regulations are necessary to ensure that all gluten sources are identified on food labels to enable individuals with CD to make informed decisions when purchasing foods.
 5. Greater cooperation and collaboration among CD support groups is required to ensure that consistent, evidence-based information is disseminated to patients, health care professionals, media, and others, as well as a strong, unified voice when lobbying government for enhanced labeling regulations and MNT coverage for CD management.
 6. Food manufacturers and the food service industry need further education and training regarding CD and the GFD.
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