

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

SHELLEY CASE

Medical Advisory Board Member, Celiac Disease Foundation, Studio City, California; Gluten Intolerance Group of North America, Seattle, Washington; and Professional Advisory Board Member, Canadian Celiac Association, Mississauga, Ontario

**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 adults<sup>1-5</sup> and children,<sup>6,7</sup> 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<sup>3,8-11</sup> and children with CD.<sup>12</sup> 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%).<sup>11</sup> The Canadian Celiac Association Health Survey of 2618 adults and 168 children with biopsy-confirmed CD identified a number of concerns.<sup>9,12</sup> 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 al<sup>3</sup> conducted a National Survey of 1612 adults (ages

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*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.<sup>8,9,11</sup>

### 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.<sup>3,8–11,13</sup> 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.<sup>3</sup> 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

<b>Gluten-containing grains, starches, and flours<sup>a</sup></b>
Barley
Bulgur
Cereal binding
Couscous <sup>b</sup>
Durum <sup>b</sup>
Einkorn <sup>b</sup>
Emmer <sup>b</sup>
Farro <sup>b</sup>
Graham flour
Kamut <sup>b</sup>
Malt, <sup>c</sup> malt extract, <sup>c</sup> malt flavoring, <sup>c</sup> malt syrup <sup>c</sup>
Oats, <sup>d</sup> oat bran, <sup>d</sup> oat syrup <sup>d</sup>
Rye
Semolina <sup>b</sup>
Spelt <sup>b</sup>
Triticale
Wheat, wheat bran, wheat germ, wheat starch
<b>Frequently overlooked foods that often contain gluten<sup>e</sup></b>
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

<sup>a</sup>From: Case S. *Gluten-Free Diet: A Comprehensive Resource Guide*, 2004, Case Nutrition Consulting, Regina, SK., Canada.

<sup>b</sup>Types of wheat.

<sup>c</sup>Derived from barley.

<sup>d</sup>Oats are not recommended by celiac groups in North America due to cross contamination with wheat or barley.

<sup>e</sup>Adapted from: *Quick Start Diet Guidelines*, Celiac Disease Foundation and Gluten Intolerance Group of North America, 2004.

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