



*A Winning
Attitude Toward*
LIVING
GLUTEN-FREE

*Coping with celiac disease
is emotionally challenging,
but an optimistic outlook
can ultimately prevail.*

BY KATE JACKSON

Celiac disease (CD) is characterized by an inability to tolerate gluten, a protein found in rye, barley, wheat, and perhaps oats. All that's needed to tame the disease is a diet free of gluten. It sounds simple enough, but as anyone who's tried it will testify, coping with gluten intolerance is no easy matter. To fully escape the symptoms and consequences, affected individuals must adhere strictly—and for life—to diets that do not permit bread, cookies, crackers, cake, pasta, pizza, and a host of other foods.

Patients with CD face a range of practical challenges and emotional repercussions to the disease itself and to the diet it necessitates. Fortunately, registered dietitians can help those with gluten intolerance meet the challenges of living gluten-free by empowering them with dietary strategies and coping resources.

While many think of celiac disease as a benign food intolerance, left untreated, it can lead to the development of symptoms related to the digestive tract and can affect the nerves, bones, fertility, hormones, skin, night vision, and blood clotting, says Joseph Murray, MD, a Mayo clinic gastroenterologist and specialist in the disease. In addition, it can cause vitamin deficiencies, anemia, osteoporosis or bone disease, and neurologic problems. Its most serious consequence, although uncommon, is a slightly increased risk of malignancies.

The Long Road to Diagnosis

According to Danna Korn, author of *Wheat-Free, Worry-Free: The Art of Happy, Healthy Gluten-Free Living and Kids With Celiac Disease: A Family Guide to Raising Happy, Healthy, Gluten-Free Children*, the average length of time between onset of symptoms and diagnosis is 11 years in the United States. "Sadly," she says, "this type of delay dramatically increases an individual's risk of developing autoimmune disorders, neurological problems, osteoporosis, and even cancer."

CD, until recently, was considered to be a very rare condition among Americans. According to Murray, data from work that's been done in the counties surrounding the Mayo Clinic suggest that the diagnosis is being made more often than it was 10 years ago. It's uncertain, however, if it's truly more prevalent now. "It's not clear whether we're finding it because we're looking harder or because more cases are occurring." Because it's been considered uncommon in the United States, there hasn't been a great deal of attention paid to the condition, says Murray, who adds that "there hasn't been any kind of wellspring of expertise that's passed on to the next generation of medical trainees. In medical

school, it's so hard for a disease like this to compete with cancer, heart disease—the big killers. So, while CD is not as rare as we might think, it's crowded out of medical education by these other things." If doctors believe it to be rare, he explains, they won't be inclined to look for it.

Some individuals may have the disease in their bodies affecting their intestines and have absolutely no symptoms for a long time. As evidence of this, says Murray, CD can be found in approximately 10% of individuals with family members diagnosed with CD, but one-half of them will have no symptoms. When symptoms do occur, they most commonly are diarrhea, abdominal discomfort (severe pain after eating, bloating, or cramping), excess flatulence, lactose intolerance, weight loss, or anemia.

The discovery of anemia, says Murray, is the single most common factor leading to a diagnosis of CD. While diarrhea is

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typical, 20% of patients with CD will have constipation on a regular basis, he adds. These symptoms may cause CD to be difficult to distinguish from irritable bowel syndrome—a catchall phrase, he explains, for digestive conditions that involve abdominal pain and some disordered bowel habit, typically constipation, but occasionally diarrhea.

While it's genuinely difficult for doctors to sort through these complaints that may be vague or suggestive of a number of conditions, one particularly unpleasant telltale clue is steatorrhea, which Murray describes as "a very malodorous, bulky stool that often leaves an oil slick on the toilet water." If someone complains of that, he advises, CD should be at the top of the list of potential diagnoses. Still, steatorrhea is present in patients with CD only approximately 20% of the time. "Many doctors were taught in medical school to consider CD when it occurred, but they weren't taught to think about CD

when it doesn't occur."

Symptoms, says Korn, can be all over the board, contributing to difficulty obtaining a diagnosis. "Some people are just fatigued, have headaches, or experience joint pain. They're misdiagnosed as having chronic fatigue syndrome, fibromyalgia, unexplained headaches, or irritable bowel syndrome."

Freelance writer and CD patient Joanna Cosgrove recalls that since her chief symptom was a rash known as dermatitis herpetiformis, her road to diagnosis was more than a little bumpy. "I endured more than a few odd treatments like light therapy, steroid shots, and medicinal baths to get rid of the rash. It took over a year for someone to finally realize it was directly correlated to the food I ate," she says.

According to Murray, for every case that is diagnosed, there are probably 20 that go undetected. The difficulty in pinpointing CD is compounded by a number of factors. According to Mary Schluckebier, executive director of Celiac Sprue Association, USA (CSA/USA), "Doctors have been taught in medical school that celiac sprue is extremely rare, so it's not high on the list of culprits when presented with a patient with symptoms that mimic other diseases thought to be more common." The symptoms, says Murray, because they're not specific to the disease, don't always raise suspicion for CD. "Lots of people get diarrhea, and there are a lot of causes of diarrhea. The same is true of other symptoms such as abdominal pain, chronic fatigue, and joint pain," says Murray. Additionally, he observes, "most doctors aren't aware of the diagnosis or don't entertain the possibility. It's not on their radar screen."

Although few patients will independently make a connection between their symptoms and the ingestion of gluten, many will suspect that they have the condition after reading about it or learning about a family member—eg, a brother, sister, or cousin—who has similar symptoms and has been diagnosed. Roughly one-third of the time in newly diagnosed cases of CD, says Murray, the patient suggests the diagnosis to the doctor. The index of suspicion should be heightened for individuals who have any of the following: a family history of CD, unexplained chronic diarrhea, digestive symptoms that occur after eating, lactose intolerance, infertility, thyroid disease, osteoporosis—particularly in a young person—or immune disorders such as type 1 diabetes, Lupus, or certain forms of arthritis.

Sometimes, patients who suspect CD may eliminate gluten from their diets in an effort to self-diagnose, but it's a strategy that can backfire. "A common scenario is that a patient hears about this possibility

and avoids gluten, feels better, and then three or four months later, goes to a doctor and says, 'Do you think I could have CD? I went on the diet, and I feel a lot better.' The doctor orders a blood test or even a biopsy, which comes back negative or equivocal, and concludes that the patient doesn't have the disease," says Murray. "Wrong. The patient may still have CD, but the self-treatment has made the test results negative." On the other hand, he explains, some who feel better after eliminating gluten may not have CD, but may feel better simply because individuals with any type of digestive problem may see an improvement in symptoms simply because they're not eating as much.

The Emotional Toll

CD has the potential to significantly affect an individual's emotional life, but, observes Schluckebier, "Much of how CD affects a person emotionally has to do with how that person deals with any change in life." The emotional toll will vary from patient to patient depending on their nature, temperament, and lifestyle. "If you have patients who have been very sick for maybe 11 years, and you tell them the answer, there is relief," says Murray. "There can be joy at the fact that they can finally feel better and at the realization that they themselves can make it better with the help of a dietitian. It's the patients making themselves better, not me giving them some dangerous or powerful medication." That, he says, is the overwhelming initial emotion among people who've been sick. The next emotion, he suggests, is shock because the problem—bread, the staff of life—is causing pain.

Another typical emotional consequence, says Murray, is a grief reaction. Sometimes, he suggests, this is cloaked in denial: "It couldn't be bread, wheat, cookies, pizza, or cake. It just couldn't be." There's also anger, he says, at having a chronic disease, at healthcare practitioners for failing to diagnose them, and at food manufacturers for making it difficult to know what's in their products. Eventually, he explains, people get to the acceptance stage, at which time they can acknowledge the restrictions in their diet, but realize that they're healthy.

Another emotional consequence of celiac disease for some is social isolation, observes Murray. "So much of what we do socially involves food—school, church, sports, and even work-related activities often revolve around meals and food. It's very much a part of our social lives, and when someone suddenly can't eat bread, cookies, or cake, they lose that spontaneity, and some may feel a degree of social isolation." This, he says, "is one of the areas in which an

expert dietitian and a support group help people to adapt and be empowered rather than feeling put down."

There are specific emotional consequences for children who may feel left out at school—"the kid who always has to bring his own stuff," explains Murray. "When I was first diagnosed," says Cosgrove, "my mom would pack rice cake peanut butter and jelly sandwiches for lunch, which made me feel very self-conscious in the school cafeteria because kids constantly made fun of my 'weird' sandwiches." Thankfully, she says, there are now better gluten-free options for children and adults. "It used to be that there was a drastic taste 'learning curve' because gluten-free foods were practically unpalatable in comparison to foods we had been accustomed to prior to diagnosis. Not anymore." Educated parents and support

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groups can empower children and teach them how to get around their limitations without giving up their social activities and how to find palatable foods.

CD taps into emotional reactions linked to religion as well. "For example," says Murray, "some churches have communion that's made of wheat wafers or wheat bread, and that raises significant emotional issues among people for whom sharing communion is a very important part of their religious observance. Often, I recommend that patients work with their pastors or other religious leaders, who are often very accommodating in making allowances for them."

Adolescents, furthermore, have a very difficult time coping with celiac disease. Murray explains: "You take whatever kids have and whatever adults have and you kind of add them together—add in the adolescent hormones, the need for acceptance, and the desire not to stand out—and there's a much greater challenge for compliance with the celiac diet."

Celiac disease, acknowledges Murray, can also have a negative impact upon the family and other relationships. "It's not uncommon to see people who've divorced because they've been sick for so long." And, even intact families can have difficulty juggling the needs of the individual with CD and those with no dietary restrictions.

There are a number of questions, says Murray: "Where do you get your food and how do you cook it? If you're the main provider for the family, what do you do for yourself? Do you cook pizza for everybody else and then think about yourself afterward?" He recommends that the individuals with CD who cook for their families cook what they can eat and let everyone else eat it as well. This is especially important for working mothers or fathers who can't possibly cook two different meals. "Obviously, when people without limitations go out, they can eat whatever they wish, but core meals should not be separate."

Resources

Schluckebier says, "Now more than ever, information and resources are easily accessible. Through the Internet, one can contact the National Institutes of Health, medical libraries, and support groups such as the Celiac Sprue Association."

Support Groups

"Local and national support groups such as CSA are a wonderful place to find support," says Schluckebier. "Meeting others who have 'been there, done that' is an important part of coping." Agrees Murray: "Meeting somebody who's been through it and sharing with somebody who's already suffered from the disease and worked through it at the support group is essential for coping and adaptation."

Family and Friends

"The patient's own circle of family and friends are important as well," says Schluckebier. "When those around you understand and are supportive of your situation, it becomes 'normal' more easily," she explains. "The most helpful thing for a person with CD is an advocate—someone who will listen, support, and be a friend. Knowing that they're not in it alone goes a long way to helping celiacs cope with their disease."

Dietitians

To educate individuals with CD about the disease and its dietary restrictions, a well-educated, well-experienced dietitian is crucial, says Murray. Patients need a professional who understands the dietary restrictions, he says, but who can also evaluate their needs in the context of

Books for Patients With Celiac Disease

Gluten-Free Diet: A Comprehensive Resource Guide by Shelley Case

The Gluten-Free Gourmet Bakes Bread by Bette Hagman

Kids with Celiac Disease: A Family Guide to Raising Happy, Healthy Gluten-Free Children and **Wheat-Free, Worry-Free: The Art of Happy, Healthy, Gluten-Free Living** by Danna Korn

their lifestyles. "The way our dietitians approach, for example, a traveling salesman who eats out 200 days of the year may be very different from the way they would approach and counsel the patients who stay at home, do all the shopping, and cook for themselves," explains Murray. These are very different challenges, and dietitians are adept at providing the right strategies for the individual's circumstances and needs. "There are people who are very much into cooking and baking, and they tend to adapt very quickly once you tell them the resources they need," says Murray. On the other hand, he explains, a person who has never cooked in his life, eats out a lot, or eats food that's preprocessed or prepared is an entirely different challenge.

Another crucial way in which dietitians can help patients with CD, observes Murray, is by providing them with up-to-date resources. "It's vitally important that the information the dietitian has is up-to-date," he advises. "It should not be five years old or 10 years old. It still happens sometimes that patients get out-of-date information, and that should be tossed out."

In addition to providing resources, education, and customized dietary instructions, dietitians also play an important role, says Murray, by addressing ancillary issues. "Despite the fact that CD can cause malabsorption, a lot of people experience weight loss, and a lot of people are overweight," observes Murray. "It's not just about telling them what's gluten-free. You have to customize that to the other dietary needs." Diabetes and CD frequently overlap, he notes. "Sometimes people are concerned about cholesterol issues, and sometimes they need information on what vitamins to take or safe sources of calcium or vitamin D, which is frequently recommended for celiacs."

An equally important responsibility for dietitians is not only to refer celiac patients to support groups, says Murray, but also to actively suggest or advocate

that they join a group. "In our area and in many centers, there are one or two dietitians among a practice who deal with the CD patients," he explains. "They are often liaisons or advisors to the local support group." The groups can provide patients with exceptional resources.

The last challenge is to ensure that the celiac patient is followed. It's not enough, says Murray, to provide information. It's important, he says, to follow up either by telephone or by scheduling an appointment for a follow-up consultation because the gluten-free diet is surely the most difficult diet to teach or learn, and it's important to be sure that it's done correctly.

Additional Resources

Murray notes that there are lots of resources for patients with CD. Some, he observes, are excellent, and some are downright dangerous. Whether it's a book, group, or Web site, he advises scrutinizing resources for reliability. If something sounds too good to be true, he suggests, it probably is. Make sure that resources are reputable and up-to-date. If it's a Web site, he advises, investigate who supports the site. Is it a professional or lay organization? Is it done by an individual? If so, what's that person's background and credentials? How often is it updated? What sorts of references does it supply for statements it makes? Beware, he says, of recommendations for dietary modifications that are not based on science.

Keep Patients Focused on Hope

One of the great myths about CD, suggests Korn, is that the diet is impossible and horrible. "I've even heard of doctors telling patients, 'I think you may have CD, but I'm not going to diagnose you with it because the diet stinks.'" Wrong, says Korn. "It's easy to learn to love the lifestyle. It's delicious, nutritious, and no more expensive than a regular diet if you know how to shop."

It's an attitude championed by Murray. Attitude and hope do wonders, he sug-

gests. "I tell patients routinely that experiencing the aftermath of CD is like a grief reaction. I tell them, 'You have lost something in your life. You've lost the ability to go out and eat bread or sandwiches. People drive down the highway and pull in to a restaurant and get a sandwich, and you're not going to do that. So, even though you may not realize it, there will be an emotional impact from a diagnosis on how you work, feel, and travel. So, recognize that, but also think of what else you're losing: your diarrhea, how ill you feel, headaches, and chronic fatigue.'" He reminds patients that they will struggle, but that they will feel dramatically different. "It's important for us as professionals not to give negative vibes. If you tell the patient that 'this is a terrible, impossible diet,' you're consigning them to failure, and they're not even going to have a chance. They will fail right out of the box." Murray tells patients to be positive. He reminds them that they might not like the diet, but they will get better.

An informed patient with access to resources can better face the challenges of CD, and dietitians are in a prime position to empower patients with strategies, facts, and referrals. "Knowledge," says Schluckebier, "is power, and power means confidence and freedom." It's not only the dietitian's skills, but his or her attitude, says Murray, that will empower the patient. "Your attitude will make a difference right from the beginning. You've got to be enthusiastic, you've got to motivate them, and you have to show them the interest." He recalls the words of a support group leader who, at the end of her lectures, used to advise, "Send your patient off with champagne, not tears."

— Kate Jackson is a staff writer for *Today's Dietitian*.



Celiac Disease Resources

Celiac Disease Foundation
818-990-2354
www.celiac.org

Celiac Sprue Association, USA
402-558-0600
www.csaceliacs.org

Gluten Intolerance Group
206-246-6652
www.gluten.net

Gluten Freedom
www.glutenfreedom.net

Raising Our Celiac Kids
www.celiackids.com