

No Good Gluten

Even though **celiac disease** is currently incurable, those who have it take pleasure in a life that is still delectable. BY EDDIE ADELMAN



Bread. Pasta. Pretzels. Ice cream. Pizza. These are all foods that most of us ingest on a regular basis without giving it a second thought. But for some individuals, it can be the equivalent of a diabetic ingesting too much sugar. For people who suffer from celiac disease, eating any product that contains gluten can trigger a reaction that has severe health consequences.

Before Ann Delaware of Bradley was diagnosed with celiac disease in 1994, her family thought she was dying. "I was miserable," she says. "Even though I was eating regularly, I had lost 40 pounds in less than two years. I'm a fairly active person but I had so little energy and constant gas, bloating, and diarrhea. The doctors were baffled. I was fading away."

Delaware turned to the now retired Bangor gastroenterologist Dr. Phillip Hunter at Eastern Maine Medical Center. The doctor took one look at her and told her she had celiac disease. He scheduled an endoscopy to confirm his diagnosis and started her on a gluten-free diet.

"Almost immediately I could see my energy level start to increase," Delaware says. "I started to gain weight again. For the first time in years, I felt like I was getting control of my life."

Sixteen years later, Delaware is in great health and great spirits. "I believe that this diet has actually made me a healthier person in general. All the symptoms are gone and I feel like the real me again."

Celiac disease is a hereditary digestive disorder that damages the small intestine and interferes with the absorption of nutrients from food. It's triggered when someone who is allergic to gluten—a protein found in wheat, barley, oats, and rye—eats glutenous foods. Their immune system responds by damaging or destroying the hair-like protrusions that line the inner walls of the small intestine called villi. It's through these villi that nutrients are absorbed into the bloodstream. If they are compromised, malnourishment ensues.

While it's found mainly in foods and drinks, gluten may also be found in everyday products such as medicines, vitamins, envelopes, and lip balms. With the disease now permeating the public consciousness, more and more people are being tested for

it. And, consequently, more people have been diagnosed with it.

"For years, the disease was often misdiagnosed as other disorders like irritable bowel syndrome," says Dr. Dan Cassidy, a gastroenterologist at Eastern Maine Medical Center. "With more effective blood testing and biopsies today, we're able to make a much more accurate diagnosis. Because the public is more aware of it now, we're seeing patients at much earlier stages than we have in the past."

Cassidy says that when patients are first diagnosed, there is usually disappointment that they will have to give up certain foods. "But once they realize the amount of food options they have, and how much better they'll feel, they begin to accept it," he says.

The food industry has responded to the vast number of Americans suffering from celiac disease with a wide variety of gluten-free products. For some food manufacturers like Glutino, Bob's Red Mill, Annie's Naturals, and Nature's Path, it's become a cottage industry.

Caryn Knudsen has been the grocery manager at the Belfast Co-op store for the last six years and has seen some major shifts on the shelves.

"About four years ago we started to stock gluten-free items," Knudsen says. "It started as a trickle, but about two years ago it really took off. We've now got gluten-free items all over the store. Cereals, burritos, cookies, soups, waffles, baking mixes, tortillas, frozen pizzas. We sell at least 500 gluten-free items a week. And we also pre-order items that our customers can't find anywhere else."

Not surprisingly, with the increased awareness of celiac disease, support groups around the country have sprung up. One of the oldest is right here in Bangor.

Dietitian Katherine Musgrave, RD, has been spearheading the gluten-free support group in Bangor since the late 1980s. The group meets once a month to encourage and inspire newly diagnosed members, as well as to enjoy the camaraderie of others with celiac. The group members exchange information about the latest food items to

hit the market, as well as restaurants that cater to gluten-free diets. They also trade recipes and bring in food samples to share. The group is so popular that they have

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members coming from as far away as Ellsworth, Dover-Foxcroft, and Belfast.

Many people who find the Bangor support group are at the end of their rope, Musgrave says. "Some have been misdiagnosed for years. I remember one of our members came to us totally frustrated. Nothing had worked. And within 24 hours of starting the diet, she was already feeling the positive effects. Within weeks, she was like a new person."

Even though Musgrave doesn't have celiac disease, she still loves being a part of the support group. "I can't tell you how relieved so many newcomers feel when they learn that they don't have to deprive themselves of foods that they love. The quality of their life doesn't have to change. It's just a matter of eating smart." □



Gluten-free items have their own aisle space at the Hannaford on Union Street.