



ajc.com
The Atlanta Journal-Constitution

 PRINT THIS

[ajc.com](#) > [Print Edition](#)

When wheat is enemy No. 1

Eating out tough, but awareness of celiac increasing

By [John Kessler](#)

The Atlanta Journal-Constitution

Published on: 04/06/08

Shaun's restaurant in Inman Park is the kind of intimate spot where guests at neighboring tables might strike up a conversation. But on a recent Sunday night, Dora Burke and Jennifer Harris not only swapped notes on the prix fixe dinner, they compared the diagnoses that had brought them to it.

Burke has rheumatoid arthritis, Harris celiac disease. Both had come to Shaun's for the chef's special gluten-free menu — a monthly draw for both the gluten-intolerant and the gluten-free curious from around the city.

Diners in large numbers are turning to diets devoid of wheat, rye and barley for a host of reasons, but particularly because they suffer from celiac disease, an inherited autoimmune illness that affects an estimated one in 133 people. So restaurants have responded with menus that not only cater to the gluten-free diet but also invest it with a measure of gastro-glamour.

At Shaun's, diners can enjoy a four-course chef's menu with paired gluten-free beers. The Four Seasons Hotel serves a lavish gluten-free high tea with chickpea scones and rice-bread finger sandwiches. Others, such as Eclipse di Luna, prepare special menus for gluten-free dining and social groups. Even at Outback Steakhouse, the Chocolate Thunder From Down Under is made without a speck of wheat.

"And there's no gluten at all in the coating of the pan," boasts Outback co-founder Tim Gannon.

Such minute details may be vitally important to sufferers of celiac, for whom a pleasant meal out could become an ordeal because of a misinformed waiter or sloppy cook.

"Say they flip your food with a spatula that just flipped a pancake," says Harris. "Then, hey, they just cross-contaminated you. For some people, that means they might not be able to get out of bed for three weeks."

A 'chameleonlike illness'

Celiac afflicts different people with varying degrees of severity but also with completely distinct symptoms. Many patients first complain of some form of gastrointestinal distress, but others experience anemia, weight loss, hair loss, osteoporosis, infertility and depression. Further complicating matters: About 98 percent of gene carriers, or about 2 million Americans, don't yet realize they have the condition.

"It's a chameleonlike illness," says Dr. Cynthia Rudert. A medical adviser to the Celiac Disease Foundation, Rudert follows more than 500 patients in her Atlanta gastroenterology practice and travels the country to raise awareness among physicians. "The problem is that sufferers are often languishing under the wrong diagnosis, such

as irritable bowel syndrome. The average delay in diagnosis is 11 years."

That means many people suffer for years before discovering the culprit is gluten — the wheat protein strands that link, arm in arm, like those plastic apes in the Barrel of Monkeys game, to make dough elastic.

In celiac patients, gluten attacks the small intestine, specifically by breaking off the millions of fingerlike projections that line it called villi (pronounced vil-EYE). Without villi, people can't absorb important nutrients, such as calcium. The digested food rushes past, says one celiac sufferer, "like a bucket of water on a tile floor." Once patients eliminate gluten, the villi usually regenerate.

Rudert calls celiac a "lock and key" disease. People inherit a gene that predisposes them, but they need a trigger to activate the full-blown illness. A simple genetic test can determine if you're susceptible, but only an endoscopy and cell biopsy can show the broken villi.

The trigger may be stress, trauma, environmental factors or an overindulgence in gluten. For Harris, a cross-country move from Arizona was the trigger. Her problems started in the car. After three years of distress and umpteen doctor visits, she got the verdict.

Saying goodbye to wheat

For many, the diagnosis is an emotional trial.

"I just went home and cried," says Lisa Gray of Tucker, whose diagnosis came three years ago when her doctor looked into a seeming case of acid reflux. "Then I went to Whole Foods and got some gluten-free bread and crackers and — yuck! — I just didn't like them."

With gluten in a third of the typical American diet, finding substitutes and saying goodbye to favorite foods can be traumatic.

"When my kids were little," quips Gray, "I used to say I wouldn't care if I never saw another piece of pizza. Isn't that a case of 'Be careful what you wish for?'"

In her first forays into food shopping, Gray discovered a gluten land mine at the supermarket. One brand of barbecue potato chips was off-limits, but another was fine. Kikkoman soy sauce? No go.

Special gluten-free products offered little solace. Gray deemed rice-flour pasta "nasty," while she found gluten-free Ritz-like crackers good, but prohibitive at \$6.50 a box. As far as gluten-free breads bound with gums and emulsifiers, Gray found them "generally awful." Some improved with toasting, but of course Gray couldn't use the family toaster for fear of cross-contamination.

On her doctor's advice, she hasn't yet tested her children — ages 12, 14 and 15 — because they are currently asymptomatic, and she figures "they'd cheat all the time." Road-trip meals, meanwhile, have become a search for an Outback Steakhouse or P.F. Chang's outlet, restaurants that offer gluten-free dishes on their menus.

The good news? After eliminating gluten, Gray feels better, has more energy and no longer suffers from the mouth ulcers and migraines that plagued her.

"The vast majority of my patients feel so much better after adopting the diet," says Rudert. "After that, they almost see gluten as a poison."

Wider awareness needed

Indeed, the psychology of going gluten-free is akin to ending an unhealthy relationship that has gone on far too long. New members celebrate the "gluten-free lifestyle" by joining support and social groups, arranging fancy dinners and learning how to indulge in food all over again.

Gluten-Free Girl (gluten.freegirl.blogspot.com) has become one of blogdom's great successes, generating a book deal for author Shauna James Ahern, who writes with grace about the pleasures of eating and with candor about celiac. "Her groupies are more fanatic than Bob Dylan's," opines Amateur Gourmet blogger Adam Roberts.

The annual Gluten-Free Culinary Summit draws hundreds of people to a long weekend of lectures, cooking classes and fancy meals prepared by, among others, an instructor at the Culinary Institute of America and the chef from luxury spa Canyon Ranch in Lenox, Mass. (The summit's third edition will be Sept. 19-21 in Providence, R.I.)

Here in Atlanta, a gluten-free group formed through the online network Meetup.com regularly hops about the city's trendy restaurants.

Which raises the question: What about poor people who may have the illness? Suzanne Bowland, who organizes the Gluten-Free Culinary Summit, defends the gathering's highfalutin tone because its mission is "bringing more awareness through the culinary arts."

"When you start high at the culinary level, it somehow starts trickling down," she says. "It brings awareness to the masses."

Perhaps, but for now, people with money and resources are more likely to obtain the still-difficult diagnosis.

"I went to the doctor 13 times in one year before I was correctly diagnosed," says Tiffany Janes, who runs the Atlanta gluten-free Meetup group. "Maybe not a lot of women can take that much time off."

Rudert also notices the income discrepancy in diagnosis. She is aware of only one medical institution — the University of Chicago — that conducts an annual community outreach program for celiac awareness.

Rudert also notes that the United States lags far behind Europe and Canada. "I've heard you can go into a McDonald's in Finland and get a gluten-free bun. We need that here."

Still, it's clear that along with some restaurateurs, retailers are beginning to get the message, too. Kroger supermarkets, for instance, are beginning to advertise the array of gluten-free products they carry.

Grilled cheese, please

But as awareness of the gluten-free diet grows in America, so does the number of people who try it out as the latest diet fad.

"I see people that will come to me and say they think they're gluten sensitive, but they don't have celiac," Rudert says. "It can be hard to answer."

Rudert says it a good rule of thumb to cut back on gluten if you eat a lot of bread and pasta, since overindulgence might be a trigger to set off the disease.

If that happens, then you can't have any.

"Sometimes," says Gray, picking at a pretty but cardboardlike tea sandwich at the Four Seasons, "I just want a grilled cheese. You know? Just a grilled cheese."

CELIAC 101

How many people have celiac?

According to a 2003 study by Dr. Alessio Fasano at the University of Maryland, published in the Archives of Internal Medicine, one in 133 Americans is affected by the ailment. More women than men are affected.

How many have been diagnosed?

About 2 percent by most estimates, or about 50,000 people. About 2 million don't yet know they have the condition.

How is celiac disease diagnosed?

Two ways: A genetic test can show the inherited condition. But the full-blown illness with small intestine damage occurs only after a trigger sets it off. Only a cell biopsy will show this.

What is gluten?

It is a protein found in wheat, rye and barley. It is the same protein that makes doughs springy.

Are these the only foods you need to cut out for a gluten-free diet?

Yes, but wheat can also infiltrate many processed foods, such as rolled oats, soy sauce and potato chips.

What are good sources of information?

In Atlanta, your first stop should be Atlanta Metro Celiacs (www.atlantametroceliacs.org). Nationally, look at Web sites for the University of Chicago Celiac Disease Center (www.celiacdisease.net) and the Celiac Disease Center at Columbia University (www.celiacdiseasecenter.columbia.edu).

Source: Atlanta Metro Celiacs

Vote for this story!

Find this article at:
<http://www.ajc.com/living/content/printedition/2008/04/06/celiac0406.html>

Check the box to include the list of links referenced in the article.



WINMARK HOMES

UP TO **20%** OFF YOUR NEW HOME

OFFER ENDS 5/31/08!

CLICK NOW TO SAVE 20%