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## Gluten-Free, Whether You Need It or Not

By **KENNETH CHANG**

Eat no wheat.

That is the core, draconian commandment of a [gluten-free diet](#), a prohibition that excises wide swaths of American cuisine - cupcakes, pizza, bread and macaroni and cheese, to name a few things.

For the approximately one-in-a-hundred Americans who have a serious condition called [celiac disease](#), that is an indisputably wise medical directive.

Now medical experts largely agree that there is a condition related to gluten other than celiac. In 2011 a panel of [celiac experts convened in Oslo](#) and settled on a medical term for this malady: non-celiac gluten sensitivity.

What they still do not know: how many people have gluten sensitivity, what its long-term effects are, or even how to reliably identify it. Indeed, they do not really know what the illness is.

The definition is less a diagnosis than a description - someone who does not have celiac, but whose health improves on a gluten-free diet and worsens again if gluten is eaten. It could even be more than one illness.

"We have absolutely no clue at this point," said [Dr. Stefano Guandalini](#), medical director of the University of Chicago's [Celiac Disease Center](#).

Kristen Golden Testa could be one of the gluten-sensitive. Although she does not have celiac, she adopted a gluten-free diet last year. She says she has lost weight and her allergies have gone away. "It's just so marked," said Ms. Golden Testa, who is health program director in California for the Children's Partnership, a national nonprofit advocacy group.

She did not consult a doctor before making the change, and she also does not know whether avoiding gluten has helped at all. "This is my speculation," she said. She also gave up sugar at the same time and made an effort to eat more vegetables and nuts.

Many advocates of gluten-free diets warn that non-celiac gluten sensitivity is a wide, unseen epidemic undermining the health of millions of people. They believe that avoiding gluten - a composite of starch and proteins found in certain grassy grains like wheat, barley and rye - gives them added energy and alleviates chronic ills. Oats, while gluten-free, are also avoided, because they are often contaminated with gluten-containing grains.

Others see the popularity of gluten-free foods as just the latest fad, destined to fade like the

Atkins diet and avoidance of carbohydrates a decade ago.

Indeed, Americans are buying billions of dollars of food labeled gluten-free each year. And celebrities like Miley Cyrus, the actress and singer, have urged fans to give up gluten. "The change in your skin, physical and [mental health](#) is amazing!" she [posted on Twitter](#) in April.

For celiac experts, the anti-gluten zeal is a dramatic turnaround; not many years ago, they were struggling to raise awareness among doctors that bread and pasta can make some people very sick. Now they are voicing caution, tamping down the wilder claims about gluten-free diets.

"It is not a healthier diet for those who don't need it," Dr. Guandalini said. These people "are following a fad, essentially." He added, "And that's my biased opinion."

Nonetheless, Dr. Guandalini agrees that some people who do not have celiac receive a genuine health boost from a gluten-free diet. He just cannot say how many.

As with most nutrition controversies, most everyone agrees on the underlying facts. Wheat entered the human diet only about 10,000 years ago, with the advent of agriculture.

"For the previous 250,000 years, man had evolved without having this very strange protein in his gut," Dr. Guandalini said. "And as a result, this is a really strange, different protein which the human intestine cannot fully digest. Many people did not adapt to these great environmental changes, so some adverse effects related to gluten ingestion developed around that time."

The primary proteins in wheat gluten are glutenin and gliadin, and gliadin contains repeating patterns of amino acids that the human digestive system cannot break down. (Gluten is the only substance that contains these proteins.) People with celiac have one or two genetic mutations that somehow, when pieces of gliadin course through the gut, cause the immune system to attack the walls of the intestine in a case of mistaken identity. That, in turn, causes fingerlike structures called villi that absorb nutrients on the inside of the intestines to atrophy, and the intestines can become leaky, wreaking havoc. Symptoms, which vary widely among people with the disease, can include [vomiting](#), chronic [diarrhea](#) or [constipation](#) and diminished growth rates in children.

The vast majority of people who have celiac do not know it. And not everyone who has the genetic mutations develops celiac.

What worries doctors is that the problem seems to be growing. After testing blood samples from a century ago, researchers discovered that the rate of celiac appears to be increasing. Why is another mystery. Some blame the wheat, as some varieties now grown contain higher levels of gluten, because gluten helps provide the springy inside and crusty outside desirable in bread. (Blame the artisanal bakers.)

There are also people who are allergic to wheat (not necessarily gluten), but until recently,

most experts had thought that celiac and wheat allergy were the only problems caused by eating the grain.

For 99 out of 100 people who don't have celiac - and those who don't have a wheat allergy - the undigested gliadin fragments usually pass harmlessly through the gut, and the possible benefits of a gluten-free diet are nebulous, perhaps nonexistent for most. But not all.

Anecdotally, people like Ms. Golden Testa say that gluten-free diets have improved their health. Some people with diseases like [irritable bowel syndrome](#) and [arthritis](#) also report alleviation of their symptoms, and others are grasping at gluten as a source of a host of other conditions, though there is no scientific evidence to back most of the claims. Experts have been skeptical. It does not make obvious sense, for example, that someone would lose weight on a gluten-free diet. In fact, the opposite often happens for celiac patients as their malfunctioning intestines recover.

They also worried that people could end up eating less healthfully. A gluten-free muffin generally contains less fiber than a wheat-based one and still offers the same nutritional dangers - fat and sugar. Gluten-free foods are also less likely to be fortified with vitamins.

But those views have changed. Crucial in the evolving understanding of gluten were the [findings, published in 2011](#), in The American Journal of Gastroenterology, of an experiment in Australia. In the double-blind study, people who suffered from irritable bowel syndrome, did not have celiac and were on a gluten-free diet were given bread and muffins to eat for up to six weeks. Some of them were given gluten-free baked goods; the others got muffins and bread with gluten. Thirty-four patients completed the study. Those who ate gluten reported they felt significantly worse.

That influenced many experts to acknowledge that the disease was not just in the heads of patients. "It's not just a placebo effect," said Dr. Marios Hadjivassiliou, a neurologist and celiac expert at the University of Sheffield in England.

Even though there was now convincing evidence that gluten sensitivity exists, that has not helped to establish what causes gluten sensitivity. The researchers of the Australian experiment noted, "No clues to the mechanism were elucidated."

What is known is that gluten sensitivity does not correlate with the genetic mutations of celiac, so it appears to be something distinct from celiac.

How widespread gluten sensitivity may be is another point of controversy.

Dr. Thomas O'Bryan, a chiropractor turned anti-gluten crusader, said that when he tested his patients, 30 percent of them had antibodies targeting gliadin fragments in their blood. "If a person has a choice between eating wheat or not eating wheat," he said, "then for most people, avoiding wheat would be ideal."

Dr. O'Bryan has given himself a diagnosis of gluten sensitivity. "I had these blood sugar

abnormalities and didn't have a handle where they were coming from," he said. He said a blood test showed gliadin antibodies, and he started avoiding gluten. "It took me a number of years to get completely gluten-free," he said. "I'd still have a piece of pie once in a while. And I'd notice afterwards that I didn't feel as good the next day or for two days. Subtle, nothing major, but I'd notice that."

But Suzy Badaracco, president of Culinary Tides, Inc., a consulting firm, said fewer people these days were citing the benefits of gluten-free diets. She said a recent survey of people who bought gluten-free foods found that 35 percent said they thought gluten-free products were generally healthier, down from 46 percent in 2010. She predicted that the use of gluten-free products would decline.

Dr. Guandalini said finding out whether you are gluten sensitive is not as simple as Dr. O'Bryan's antibody tests, because the tests only indicate the presence of the fragments in the blood, which can occur for a variety of reasons and do not necessarily indicate a chronic illness. For diagnosing gluten sensitivity, "There is no testing of the blood that can be helpful," he said.

He also doubts that the occurrence of gluten sensitivity is nearly as high as Dr. O'Bryan asserts. "No more than 1 percent," Dr. Guandalini said, although he agreed that at present all numbers were speculative.

He said his research group was working to identify biological tests that could determine gluten sensitivity. Some of the results are promising, he said, but they are too preliminary to discuss. Celiac experts urge people to not do what Ms. Golden Testa did - self-diagnose. Should they actually have celiac, tests to diagnose it become unreliable if one is not eating gluten. They also recommend visiting a doctor before starting on a gluten-free diet.

*This post has been revised to reflect the following correction:*

***Correction: February 4, 2013***

*An earlier version of this article misspelled the surname of Thomas O'Bryan. It is O'Bryan, not O'Brien.*