

Kim Maes doesn't take it personally, at least not anymore. She knows that when her husband and son seem to be ignoring her requests to take out the garbage or put a load of laundry through, chances are they aren't being consciously stubborn or forgetful. Their brains just can't help it.

"What did you have for lunch today?" the nutritionist is inclined to ask them, hands on her hips. "Did you get glutened?"

Both Kurt Maes, a 38-year-old commercial property developer in Arizona, and Conner, who is 8, have celiac disease. Whenever their immune systems detect the presence of gluten, a common protein found in wheat, barley and rye products, they go into attack mode, inflaming and damaging the lining of their small intestines. Both the Maes fellows suffer from symptoms that are not usually considered with the condition, such as absentmindedness and the inability to complete even the most simple of tasks.

Conner was diagnosed first. Although he had suffered digestive problems since infancy, celiac disease was not spotted as the culprit. But when he began to suffer seizures at night, his parents turned to a neurologist. She looked at his brain scans, saw the damage to his cerebellum and quickly realized she had seen these kinds of abnormalities before in patients with the autoimmune condition. Testing then confirmed her suspicions.

Kurt tested positive for celiac disease the following year. Suddenly, a lot of things made sense. Like the diagnosis of attention deficit disorder he'd been given back in college. Like the so-called dairy allergy that made him double over in pain after eating foods such as pizza. Sometimes his mind seemed to wander, right in the middle of an important conversation. He wasn't a bad listener or allergic to dairy – never mind the ADHD. The abdominal pain and the behavior tics were digestive and neurologic indicators of a condition with a myriad of symptoms and only one known treatment: go gluten-free.

"There were times when it was so frustrating. I'd say, 'Are you even listening to me?'" she recalls with a laugh about the man she has been with for 19 years. "After going off gluten, Kurt was a changed man – for the most part."

Remember the old "this is your brain" anti-drug campaign with the egg sizzling in a fry pan? Think of this as the celiac/gluten-sensitive equivalent: "This is your brain – and this is your brain on gluten."

Dr. Marios Hadjivassiliou, the consultant neurologist at Royal Hallamshire Hospital in Sheffield, England and a pioneer in how gluten affects the brain, suggests that we think of the grey matter in our

brain as the computer and the white matter as the cables that hook it all up and keep it going. His latest research shows that the brain scan of someone with gluten-related damage from celiac disease or gluten sensitivity may show various degrees of damage. Sometimes he sees lesions in the white matter. In the advanced case of someone with celiac disease that has gone undiagnosed for years, the brain may even undergo a significant decline in grey matter density.

Research into how gluten affects the brains of those with celiac disease and gluten sensitivity is still in its infancy, including why symptoms are triggered in the brains of some but not others. The question may seem as puzzling as celiac disease itself, which has symptoms that mimic so many other conditions. But specialists such as Hadjivassiliou and Dr. Daniel Leffler, a gastroenterologist at Beth Israel Deaconess Medical Center in Boston, are beginning to close in on the answers.

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With grey matter damage, you may have balance issues, problems speaking or sensory symptoms. With white matter damage, you may suffer headaches as intense as migraines, have tingling sensations in your arms and legs, experience extreme fatigue or suffer from insomnia.

Then, there are the cases of accidental "glutening," such as the episodes that Kurt and Conner Maes occasionally experience. Known informally as "brain fog" or "foggy brain," they feature a temporary, often severe inability to think clearly and perform tasks. Even though a person who's trying to follow a gluten-free diet may feel thickheaded and groggy, there should be no lasting damage once the protein is cleansed from the system. While mild cases won't show up on brain scans, Hadjivassiliou's research suggests that repeated incidents of trying to "cheat" the diet could lead to more serious, long-term brain effects.

Leffler, of Beth Israel Deaconess Medical Center, is in the midst of analyzing data from more than 1,000

responses to a survey conducted in conjunction with the National Foundation for Celiac Awareness about brain fog. As respondents to the survey were among the NFCA's online community and presumed to follow a gluten-free diet, his team has been able to estimate that it takes anywhere from 30 minutes to eight hours for brain fog symptoms to appear after gluten exposure. On average, they last between four and eight hours, although they can persist for up to two days.

"It's not one thing, but probably a syndrome – one where people feel that they are cognitively limited," Leffler explains. "It could be problems taking directions, compiling lists or multi-tasking, all of which fall under the brain's executive, or a more high-performing function. Some describe how they can't even go shopping!"

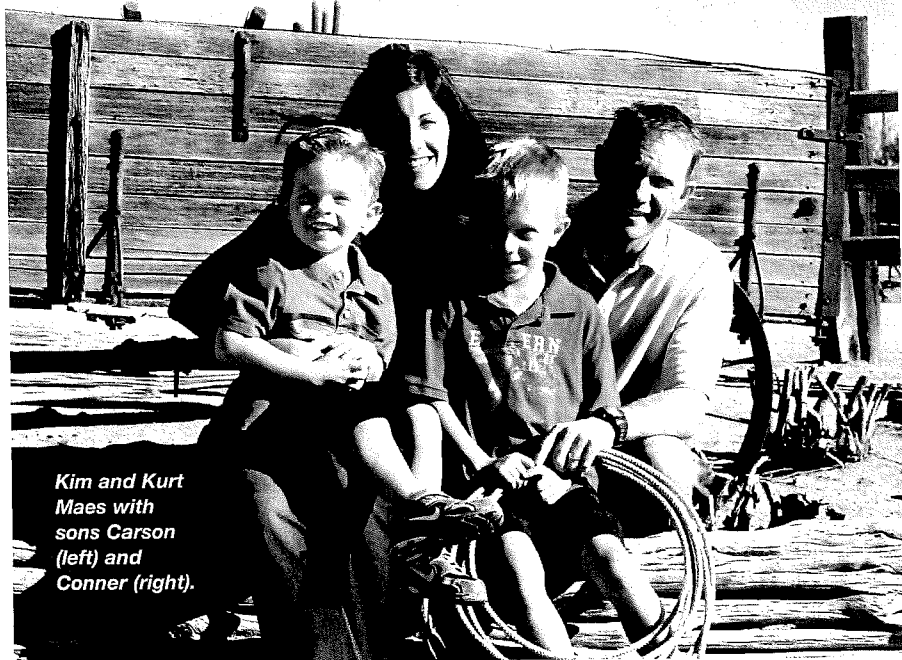
"The best analogy," he continues, "is hepatitis C patients and the side effects they experience when treated with Interferon shots ... they can feel thickheaded, fatigued and slow, as if suffering from a major cold or flu."

Leffler believes it's time brain fog and other cognitive symptoms got more attention in the medical community. "This is an issue that is very real and very common and the big problem is misdiagnosis because it just doesn't get enough attention." Another problem is that the U.S. Food and Drug Administration is still reviewing a proposed new standard for gluten-free labeling on foods. This means people who follow a gluten-free diet often have a hard time gauging what is safe to eat and what isn't. "Everything should be more clearly labeled than it already is," the gastroenterologist says. "At the very least, gluten content should be easily found on a product's website."

Shirley Braden agrees that being able to tell that your diet truly is gluten-free is of critical importance. The 56-year-old cut gluten from her diet nine years ago after what seemed like a lifetime of health issues, including headaches and hormonal swings, a hysterectomy at age 46 and having her gallbladder removed. Friends and colleagues treated her with kid gloves, for she tended to be moody at best and a downright crank when under the weather.

"People would ask things like, 'Is it *that* time of the month?' It was infuriating," she says. "The reality is, I'm not that person at all. Off gluten, I'm very positive."

These days Braden, who authors the blog glutenfreeeasily.com, still gets accidentally glutened. But the difference is that she now recognizes the symptoms. Like getting sleepy at ridiculously early hours or having restless legs that can't be relieved no matter how much she tries to stretch and relax them. Or not being able to walk in a straight line, banging into furniture as she tries to make her way across a room.



Kim and Kurt Maes with sons Carson (left) and Conner (right).

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"I'll think 'Uh-oh. We ate out today. You try to put up your guard but sometimes, it isn't enough."

Back in Phoenix, Conner and Kurt Maes have learned over the years through trial and unwitting error to be vigilant about what they eat. To better understand the condition and the diet, Kim Maes went back to university to get a Master's degree in nutrition. She has since become a food allergy coach and created a website (www.allergyfreefoodcoach.com) and a healthy cooking app for smartphones.

"It has been a real lifestyle change for all of us," she says. "At home, it's easy to know the content of everything we put in our mouths. Outside our kitchen, it's not always as easy."

For example, Maes recently spent a day fretting because Conner had a cultural event at school, complete with food stations that represented different nationalities. Would he inform himself of what was in each dish before trying it? When he came home, she kept watch over him, anxious.

But he reassured her. "Mom, I must've known what not to eat today," he said. "I feel good. I feel like me!"

Do you get brain symptoms when accidentally glutened? Let us know at editor@allergicliving.com.