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Going gluten free in Eagle County

How locals are coping with celiac disease

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[SARAH MAUSOLF](#)

SMAUSOLF@VAILDAILY.COM

VAIL CO, COLORADO

EAGLE COUNTY, Colorado — Julie Shedko has had trouble with food for as long as she can remember. As a child, stomach aches, migraines and “brain fog” plagued her when she ate.

“I was raised on carrot juice because they couldn’t figure out what was wrong,” the 46-year-old Eagle-Vail resident said. “I was allergic to everything but they just said it was dairy so I continued eating all the other things.”

Doctors told her she had irritable bowel syndrome, migraines or sinusitis. But Shedko suspected another cause.

“I knew it was more than that,” she said. “You kind of feel crazy.”

About three years ago, Shedko reached a breaking point. She had been eating normally, but dropped 40 pounds in less than three months. Her weight dipped to a skeletal 107 pounds on

a 5-foot-7-inch frame.

Frustrated, Shedko turned to Deborah Wiancek, a naturopathic physician based in Edwards, who gave her a blood test for celiac disorder. An increasingly common but frequently overlooked condition, celiac disorder is a total intolerance to gluten — proteins in wheat, rye or barley. Celiac disease can prevent the body from properly absorbing nutrients, leading to weight loss.

For Shedko, finding out she had celiac disorder came with mixed emotions.

“It kind of validated that I wasn’t out of my mind, but I knew I was in for a challenge because you have to eat three or four times a day and how was I going to do that?” she said.

The only treatment for celiac disease is purging gluten from the diet, a task Shedko knew would be tough. A year ago, she started a local branch of the Los Angeles-based Celiac Disease Foundation. The group meets monthly at the Avon Library.

Finding support

Six members of the Celiac-Gluten Free Support Group gathered at the Avon Library Wednesday night to indulge in gluten-free treats.

The women’s stories highlight the complexities of living gluten free. Not only are common foods like pasta, bread, pizza and beer off limits, gluten can lurk in lipsticks, over-the-counter drugs, even the glue on envelopes. And sorting through the laundry list of taboo ingredients requires research.

“It’s a part-time job, especially in the beginning,” said Alix Berglund, a 35-year-old Edwards resident recently diagnosed with celiac disorder.

Although some supermarkets carry gluten-free foods, the products can be hard to find or inconsistently stocked, Shedko said.

"At first you're just thrown back into the grocery store," she said. "I can remember sitting on the floor reading labels, and someone came up to me and was like, 'Man you must have a food allergy.' It would take me hours to shop."

When it comes to picking the right foods, the stakes are high for the gluten intolerant. People with celiac disease say they suffer dearly when they eat gluten.

"I describe it as a sword fight in my stomach," said Mindy McNitt, a 31-year-old Edwards resident who has celiac disease.

Faced with these unique challenges, the women take comfort in getting together to trade recipes, share their stories and discuss the latest celiac research.

Shedko appreciates "having something in common with someone instead of just feeling different all the time."

The quest to eat out

One of the celiac support group's top priorities is convincing local restaurants to offer gluten-free options.

"I would like to challenge them to bring gluten-free items to their menus," Shedko said. "We're not asking for a lot. We don't need a lot of variety. It's just nice to be able to go there with our family and pick something and be able to eat in that environment."

Some restaurants have already added gluten-free foods to their menus. Shedko lists Juniper, Larkspur, Terra Bistro, Larkburger, Dish and Avondale among the eateries that offer gluten-free options.

She also worked with Vail and Beaver Creek resorts to incorporate gluten-free options at the mountain eateries.

Long road to diagnosis

At 22, McNitt knew something was wrong. Although she was a marathon runner, she suffered from early onset osteoporosis and anemia.

"We took a picture of the whole family and I was white as a sheep," she recalled. "My mom said 'Something's wrong with you.'"

Doctors agreed, but they struggled to pinpoint the problem.

"Good grief. They tested me for mono, for everything," McNitt said. "They thought I was dying of something. They didn't know what was wrong with me."

Eight years ago, doctors tested McNitt for celiac disease, but only after McNitt insisted on it because her aunt had recently been diagnosed with the disease (the condition is hereditary.)

Celiac diagnoses rarely come quickly. In fact, it takes nine years on average for a person to receive the correct diagnosis, said Elaine Monarch, executive director of the Celiac Disease Foundation.

"There's one paragraph in the medical books about it," she said.

Complicating the diagnosis, celiac symptoms mimic other gastrointestinal disorders, like irritable bowel syndrome, Monarch said. Two years ago, Berglund was diagnosed with cancer. When she started to experience severe stomach problems, doctors insisted they were a side effect of her cancer drug. One specialist even accused her of being anorexic before she discovered she had celiac disease.

Monarch estimates that 97 percent of people who have celiac disorder don't know they have it. Left untreated, celiac disease can lead to early onset osteoporosis, infertility, unexplained anemia, vitamin deficiencies and dental enamel defects.

The disorder affects 1 in 133 Americans, or roughly 3 million people, she said.

Symptoms of celiac disorder include recurring bloating, gas, chronic diarrhea, unexplained weight loss and anemia. The cause is unknown and no cure exists, Monarch said. However, doctors know the disorder is genetic. Kimball Genetics in Denver offers a test to determine whether a person is susceptible to celiac disease. A blood test or small bowel biopsy can confirm that a person has celiac disease.

In recent years, information on celiac disorder has become more plentiful. Gluten-free cookbooks, grocery guides, cooking classes and products continue to proliferate.

“Within this next year, there’s going to be 25 percent more gluten-free products out on the market, and I think even in the Western world of medicine, they’ve really come a long way with tying this together,” Shedko said.

High Life Writer Sarah Mausolf can be reached at 970-748-2938 or smausolf@vaildaily.com.

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