

Coeliac disease affects 1 in 100 New Zealanders. Yet four out of five people don't know they have it, and live undiagnosed with bewildering symptoms

# IS GLUTEN YOUR ENEMY?

BY LISA FITTERMAN

**T**he terrible stomach-aches began when Satu Kettunen was 17 years old. When the teenager saw her family doctor, he attributed the pain to her nervous disposition. "It will get better as you get older," he said.

But it didn't. Nothing helped – eating less, eating more, fasting, and even doing yoga. Finally, four years later, unable to bear the pain any longer, Satu went to see a different doctor. This doctor ordered a blood test. When it showed antibodies to gluten, Satu then underwent an intestinal biopsy that quickly



**Sisters Satu (top) and Outi Kettunen – one had classic symptoms, the other none at all**

confirmed the diagnosis. Satu had coeliac disease.

Until the 1980s, much of the medical community dismissed coeliac disease as a childhood digestive disorder, the only symptoms widely recognised being constipation or diarrhoea, bloating, stomach pain and cramping.

"Coeliac disease is now recognised as a condition that can occur in people of any age," says Carole Chamberlain, secretary of Coeliac New Zealand. She should know the ins and outs: both Chamberlain and her daughter are in fact diagnosed coeliacs.

Although the condition is now more readily identified and diagnosed by

## Latest research

Predicting the future of coeliac disease is like watching a movie with alternate endings. Treatment could be a series of vaccines; an oral enzyme that breaks gluten down before it reaches the small intestine; or groceries that contain wheat but have been genetically modified to neutralise gluten. Here's the latest research from around the world:

» **Tampere, Finland** Markku Mäki, paediatrics professor and a top coeliac researcher, recently completed a small clinical trial of the drug ALVoo3 that reduced the damage even minute particles of gluten can cause to the small intestine lining. The next step? A larger patient trial.

» **University of Leiden, Holland** Researcher Frits Koning tested an enzyme called prolyl endoprotease (or PEP), a substance that is known to break down gluten, on 14 patients.

» **Cambridge, Massachusetts, US** ImmusanT, a company formed to develop coeliac vaccines, is planning a second-stage safety trial for Nexvax2. The vaccine is the brainchild of Bob Anderson, a gastroenterologist who conducted the first trial in Melbourne. Patients are given injections of three specific peptides in gluten that cause a reaction in coeliac sufferers, to help them gain a tolerance.

» **Washington State University, US** Researchers are trying to breed a wheat suitable for coeliac sufferers.

» **Wendelsheim, Germany** Torsten Matthias of Aesku Diagnostics has developed peptides that can detect sensitivity to gluten up to two years earlier than blood tests can.

**“With heightened awareness and a greater understanding of what triggers coeliac, I call it the perfect storm. It’s time for change”**

**Leslie Williams,**  
President and CEO, ImmusanT

doctors, for every sufferer identified with the problem, many others remain undiagnosed. And Coeliac New Zealand reports that it's not just a problem of recognition; the incidence of coeliac disease in both children and adults appears to be on the rise.

Today much more is known about the disease and the damage it can cause. In sufferers, gluten – a protein found in wheat, barley, oats and rye products – damages the small, finger-like projections in the lining of the small intestine called villi, which help nutrients to pass into the rest of the body.

When the villi don't work properly (or at all), no matter how much or how little you eat, essential nutrients such as vitamins, minerals and phosphates aren't absorbed into the body adequately. The consequences are serious. Malnutrition, skin rashes, osteoporosis, infertility and depression can all be symptoms of undiagnosed coeliac disease.

Coeliac researcher Torsten Matthias recalls a former neighbour – a construction worker – who was in terrible pain for three years, with swollen joints and limited mobility. Diagnosed with rheumatoid arthritis, he had lost his job and his apartment.

“I asked him, ‘When do you have pain?’ The reply was when he ate pizza. So I gave him a letter for his doctor, asking that he be checked for coeliac disease,” Matthias says. “Sure enough, it was, and now he's healthy again.”

At present, the only effective treatment for coeliac disease is to remove gluten from your diet. It's not easy. The protein is everywhere, from the usual suspects like most breads, pastas and pastries to processed foods and even communion wafers. Going gluten-free isn't a foolproof solution, either. According to Dr Peter Green, professor of clinical medicine at Columbia University in the US, about 50% of those coeliac patients who scrupulously follow the diet still suffer some discomfort and ongoing intestinal damage.

Satu dutifully cut gluten from her diet. She has become fluent in the language of ingredient labels and menus, and she reads constantly to keep up with research. She was happy to learn that the villi in her body are regenerating, much like a lung blackened by tar and nicotine eventually becomes pink and healthy again once an individual quits smoking.

Sometimes, though, the damage can only be halted, not reversed. Marios

## Symptoms vary in type and severity

Symptoms of coeliac disease may involve multiple organs and range widely in severity and type, from the usual suspects like bloating, constipation and diarrhoea, to anaemia, being preternaturally short, or having problems conceiving.

According to Shelley Case, a registered dietitian and author of the *Gluten-Free Diet*, other symptoms include:

- » Nausea and vomiting
- » Indigestion/reflux (heartburn)
- » Lactose intolerance
- » Weight loss (although coeliac disease can also occur in obese individuals)
- » Chronic fatigue and weakness
- » Iron, folic acid and/or vitamin B<sub>12</sub> deficiency
- » Other vitamin and mineral deficiencies
- » Bone and/or joint pain
- » Osteoporosis
- » Easy bruising of the skin
- » Swelling of hands and feet
- » Headaches
- » Mouth ulcers
- » Menstrual irregularities
- » Recurrent miscarriages
- » Elevated liver enzymes.

### Additional symptoms in children

- » Irritability and behavioural changes
- » Concentration and learning difficulties
- » Failure to thrive (delayed growth and short stature)
- » Delayed puberty
- » Dental enamel abnormalities.

Hadjivassiliou, a neurologist at Royal Hallamshire Hospital in Sheffield, England, recalls: “There was one elderly gentleman who’d had gross lack of coordination – ataxia – for 20 years, along with gastro symptoms like bloating and diarrhoea.

“Once he was diagnosed with coeliac and on the correct diet, the ataxia stabilised, but he hasn’t walked again. The part of the brain that controls movement had shrunk too much. Earlier diagnosis would have made a big difference.”

## Foods to avoid

It’s hard to go gluten-free. Of course, some foods are obvious no-nos, such as wheat, rye, barley, crackers, pastries, cakes, biscuits and doughnuts. Under rules by Food Standards Australia New Zealand (FSANZ), food manufacturers have to indicate on the ingredients panel if a product contains detectable gluten, oats or malted gluten containing cereals or their products.

In addition, some, though not all, products also have a separate “allergy box” alerting the consumer to ingredients likely to cause allergic reactions. Some surprising products contain gluten, so it’s always worth checking the label. They include:

- >> Gravy, sauces and many soups
- >> Some yoghurts and ice-creams
- >> Spices that have flour added to prevent clumping
- >> Potato chips
- >> Frozen burgers (including meat, chicken, fish)
- >> Beer and malted milk
- >> Commercial salad dressings.

Coeliac disease is a hereditary condition, although only around one in ten close relatives of a coeliac sufferer will develop it. Family members of those diagnosed are encouraged to be tested, and while self-testing kits are available in pharmacies, Coeliac New Zealand advises these tests should not be used to officially diagnose coeliac. “This test does not provide the same accuracy of results as the standard tests, but can provide a rapid way for the patient to consult their GP,” adds Chamberlain.

When Satu learned that you could have coeliac disease without having any symptoms, she thought of her sister Outi, four years her junior, who’d always eaten and drunk whatever she wanted. Could she be sick

without knowing it?

“Get tested,” Satu told her sibling in a phone call.

“But I feel fine!”

“I know. But there could be damage you’re not aware of,” replied Satu.

Finally, Outi agreed. To her shock, the test came back positive.

Johan Jansen, his daughter, Marieke Mol and his granddaughter, Charlotte Mol, learnt that you won’t necessarily have the same symptoms even if you are of the same family. Jansen, who was diagnosed in his 40s, had classic symptoms such as diarrhoea and stomach bloat, while Marieke was anaemic and Charlotte suffered from an unsightly, scaly red skin rash. Both Marieke and Charlotte suffered for years before being tested.

**Marieke Mol  
and daughter  
Charlotte  
lead full lives**



For Charlotte, whose rash disappeared when she went on a gluten-free diet at age 15, the hardest thing about having coeliac disease is that people often don't, or won't, understand. Once, she even collapsed in tears after the parents of two friends refused to prepare gluten-free meals for her. "You should be grateful for what's on your plate," they said.

Counselling helped. In a session with other coeliacs, a psychologist suggested a variety of ways to handle insensitivity and ignorance – comebacks like, "Keep it up if you want to see me end up in hospital," or, "Would you give a diabetic a sugar bomb?"

Fortunately, manufacturers have made great strides in the availability of gluten-free foods. Food Standards Australia New Zealand (FSANZ) requires any ingredient in a product derived from a gluten containing grain (wheat, rye, barley, oats) to be declared on the label. Products containing no detectable gluten should carry the FSANZ gluten-free standard.

**“We’re all  
working towards  
the same goal  
- to give people  
choice and a  
quality of life”**

**Markku Mäki**, paediatrics professor  
University of Tampere, Finland

Dr Markku Mäki of the University of Tampere in Finland, says that treatments other than a gluten-free diet are still five or ten years away.

“Today, the future is just to get a correct diagnosis earlier,” Mäki says. “We need to shorten diagnostic delay and reduce the long-term ill-effects.” ■

*Additional reporting by Maya Zahran*

**For more information, visit the Coeliac  
New Zealand website at [coeliac.org.nz](http://coeliac.org.nz)**