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# Big fireworks in tiny tummy

By SHANNON BEYNON

If there's one thing Melissa Milne would like people to understand about coeliac disease, it's that the condition is frighteningly real – and just as inconvenient for those suffering from it as it is for those trying to cater for them.

Milne's daughter, Paige, was diagnosed with gluten intolerance in August last year, and Milne has lost count of the number of arguments she's had with people over the need to keep gluten and gluten-free products separate.

"I just wish people would be more understanding. If I'm out at a cafe and ask the person behind the counter to use fresh tongs or clean gloves to get Paige's food, I'm not being difficult. I'm asking because the results of her having just a crumb from gluten products can be devastating."

Those effects include severe stomach cramps, extreme moodiness, diarrhoea, and exhaustion for 4-year-old Paige.

Milne visited multiple doctors over a span of years before receiving the diagnosis.

"I was made to feel like I was overreacting and a neurotic mother, but I just knew something wasn't right."

Paige had always been incredibly moody, would have four or five sleeps at preschool every day, had low self-confidence, and would not participate in group time. She gained only 0.7kg in weight in a year, and suffered constant and severe stomach pain.

"The specialist told me that it would have felt like fireworks going off in her tummy."

Paige was finally diagnosed after blood tests picked up her gluten allergy. She underwent biopsies on her oesophagus and bowel, with all eight samples returning as positive for coeliac disease. During the two weeks it took for the results to come through, Milne took to Facebook

and found a reference to coeliac on a parenting support page – the first time she had ever heard of the condition.

The family has since undergone a completely lifestyle shift.

"A supermarket shop doesn't take 20 minutes any more – it's a one-hour mission. I have to check the labels on everything, even the products that I usually buy, because ingredients can change at any time, with no notice. And it's

much more expensive now than it used to be – \$16 a week on cereal just for Paige, \$40 for gluten-free flour. It costs an extra \$100 a week just to feed Paige."

The planning, organising, and expense have been worth it, with

Paige returning a coeliac level of just 2.5 in her last test. It had been 150.

"Paige is a normal 4-year-old now. It's like I'm getting to know my child all over again. I've raised her for four years without

knowing who she really is. Within three months of being gluten free, her confidence has skyrocketed, she participates in everything – she's a new girl."

Milne's other children haven't showed signs of gluten intolerance

as yet, but her understanding is that the disease can flare up at any age.

"Something can happen, like a tummy bug or a bit of sickness, and it's like a light switch going on. The coeliac disease is then active."

Paige's little sister will now be tested at least once a year.

"I'm scared of the day Paige starts school. It's not just food I have to worry about. Things like pencils, sunblock, playdough, toothpaste can all have gluten in them. But Paige is learning and she now asks if things have gluten in them. I'm teaching her to read the labels on products. Growing up is going to be hard for her."

Milne said the diagnosis was not the relief some people think it might have been.

"I still have days when it's just too hard – I just need people to be more understanding and not argue with me about it. Arguing doesn't change anything."



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## Many living with coeliac disease

According to Coeliac New Zealand, the condition is a permanent auto-immune disorder caused by an intolerance or reaction to gluten, which is found in wheat, barley, oats, and rye. It causes the body to produce antibodies that damage the lining of the small bowel and make it impossible for the body to absorb certain vitamins, minerals, and other nutrients from food. If left

undiagnosed, it can lead to long-term chronic ill-health.

### Who gets it?

Family members of people with coeliac disease have an elevated risk of testing positive for it, as the condition is genetic. Coeliac NZ estimates 60,000 to 70,000 Kiwis are living with the illness, with around 80 per cent of those unaware they have the condition. Blood tests to look for coeliac disease are widely available, and results usually

come back within a few days.

### What are the symptoms?

Symptoms can include stomach pain, loose bowel motions, weight loss, tiredness, low iron levels, mouth ulcers, and infertility. Some people may not have any recognisable symptoms at all.

**For more information, see Coeliac New Zealand's website and Facebook page: [coeliac.org.nz](http://coeliac.org.nz) and [facebook.com/coeliacNewZealand](https://facebook.com/coeliacNewZealand).**



Melissa Milne with Paige, 4, who was diagnosed with coeliac disease last year. The condition has caused a massive lifestyle change for the family.