



Coeliac disease

A patient perspective

Thérèse Jensen

In order to help us better understand our patients' experiences, *Australian Family Physician* is pleased to introduce the third in a series of articles written by people who are willing to share their stories. Thérèse Jensen was nominated to write this article by *AFP's* Production Editor.

It sounds strange but I was actually glad when I was finally diagnosed as having coeliac disease. I had been chronically iron deficient, tired and lethargic for several years and had begun to think I was either mad or dying so it was a relief to find an answer to my symptoms. The process involved in getting to diagnosis was long and frustrating.

Having four children in 5 and a half years and working part time I expected to be tired, but when the youngest child finally went to school and I had more time to myself – and still didn't seem to get any better – I went to see my general practitioner. I had a range of tests; the only abnormality was iron deficiency. This led to a gastroscopy and colonoscopy at a procedural centre. I now suspect they totally missed my coeliac disease.

It was another 2 years before diagnosis. It was during this time that I thought I was dying or just plain 'loopy'. It was difficult on my family, particularly my husband who would cop the brunt of my frustration and grumpiness at the end of the day. A second gastroscopy was eventually done at another centre and coeliac disease was diagnosed. It was a relief to finally have an answer.

I should just say here, that I have a problem with calling this a 'disease'. I have seen the faces of people cloud over when I say I have coeliac 'disease'. There must be a better way to describe the problem.

It was a hard at first explaining to my children what coeliac disease was, but they now have a very good understanding of my dietary needs and the damage that can be done to my gastrointestinal tract should I ingest any gluten. As my symptoms did not include typical diarrhoea, bloating or pain, they sometimes wonder why I don't 'cheat' on my diet. When I tell them that I could develop bowel cancer from nonadherence they understand my strict attention to diet.

As coeliac disease is inherited, there was a one in 10 chance that one of my children might have the disease. All four children had a blood test, one tested positive. She went on to have a gastroscopy that excluded the presence of the disease, much to our relief. She will have to be monitored throughout her life, but at the moment she is able to enjoy all the foods her friends enjoy.

As I do most of the cooking at home, eating properly is not a problem. In fact, the coeliac diet is a very healthy one as I cook most things from fresh ingredients because most commercial products contain gluten. The hassles really begin when eating out. I often ring the restaurant ahead if I know where we are going to ensure that I will be able to eat a dish from the menu or if the chef is able to modify a particular dish for me. My friends and family are all aware of my needs and are happy to cook gluten free for

me. It took me a long time not to feel guilty about putting people out by my need for a special diet. Supermarket shopping does take longer as I have to thoroughly read all product labels – and it is taking longer the worse my eye sight gets – can't blame the coeliac for that!

It is now 7 years down the track from diagnosis and I feel really well. The gluten free diet has helped my gut to heal and I now absorb my food properly. I have a degree of osteoporosis so I do plenty of weight bearing exercise. The weight gain – one of the downsides to a correct diet – was a bit depressing at first, but exercise and eating the right things helps keep it under control.

My GP is great. Her mother has coeliac disease so she has a true understanding of some the difficulties encountered. As technology has made diagnosis easier, more and more people are found to have the disease. Consequently there are more gluten free products available than when I was first diagnosed, and it has become easier. There's no point having regrets, but I do feel sad about the years of feeling unwell while my children were little, when I should have been more active. However, it's good to know I'm not mad or dying, just coeliac!

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