

A Coeliac's Story

This is a story (to ignore or use as you wish) from a male resident of the Cove who ought to remain anonymous.

After a great many years of problems with greasy diarrhoea, constipation, bloating, stomach cramps, increasing fatigue and a variety of other unpleasant symptoms, I eventually visited my local doctor. The doctor, after a few tests, referred me on to a gastroenterologist. This referral letter sat gathering dust for more than a year although all the symptoms continued. After a few episodes of being doubled over with stomach pains I returned sheepishly to my doctor and was given a new referral. Yet again I found myself always too busy to make an appointment with the specialist.

Two more years went by. I complained a lot about the symptoms but did nothing. Then just a few hours before a flight to Europe I was in agony. How was I going to survive more than twenty hours cramped on a plane? With no time left to see a doctor I staggered to my chemist. He gave me something stronger than you can normally get over the counter on the condition that I promised to see a doctor as soon as I returned.

Nine months after we returned from Europe my better half ordered me to either stop complaining or get to the doctor. For once, I obeyed. I was far too embarrassed though to return to the same doctor as before.

The new doctor ordered a series of blood tests. My liver tests were all awry. My folate level failed to register. Many other blood tests were out of whack. Ultrasound did not seem to show anything amiss with the liver. The doctor rang the pathology lab for advice. Among other tests they suggested was one for Coeliac Disease. Bingo.

This time I did go to see the Gastroenterologist. The Coeliac Disease diagnosis was confirmed by a biopsy from an upper endoscopy. I was anxious beforehand about a specialist poking a long tube down my throat. Fortunately you cannot remember anything about it afterwards.

I had never heard of Coeliac Disease. What was it? How is it treated? I soon discovered that one percent of Australians have Coeliac Disease. Yet only one quarter of those with it, know that they have it! There must be many people putting up with symptoms and, like me, avoiding a diagnosis.

People with the disease have a reaction to the gluten found in wheat, rye, barley and possibly oats. Their own immune system attacks and truncates the villi, the hair-like structures that line the wall of the small intestine. Normally these villi provide a massive surface area through which nutrients are absorbed from the food we eat. With the surface area progressively reduced by Coeliac Disease, fewer essential nutrients are absorbed. This can lead to a wide variety of symptoms. Hair loss and mouth ulcers were just two of my symptoms that I discovered were being caused by the disease. My border-line Osteopenia I did not discover until the specialist sent me for bone density tests. Symptoms can vary a lot so the disease is often mistaken for something else. Untreated Coeliac Disease also increases the risk of some types of cancers.

The treatment for Coeliac Disease does not involve medicines. You just need to change your diet to eliminate any gluten from it. Then, over time, those villi will grow back and *most* sufferers will soon begin to feel a whole lot better.

There is a bit of grief in changing your diet. Five years on, I still yearn for a nice crusty loaf of bread. Regular beer is off the menu. You spend a lot of time checking the minuscule ingredients-lists on packages. Travelling and eating out can be a real hassle at times.

Mostly though, there is no reason you cannot dine as well as anyone. Wine is fine. Distilled spirits are good. Gluten free beers are refreshing. Gluten free bread is getting better. Fresh meat, vegetables, herbs and spices are all good. The list of gluten free options is growing in most supermarkets – some are near the health foods, others on the regular shelves. Australian labelling standards are excellent even if the labels are too small. The Coeliac Society (www.coeliacsociety.com.au) can provide you with support and it publishes a great quarterly magazine.

If you think that perhaps you may have Coeliac Disease please do not self-diagnose and put yourself on a gluten free diet. That will mess up the chances of an unambiguous diagnosis. Instead, talk it over with your doctor. He or she will order the appropriate blood tests if they think Coeliac Disease is a possibility. Just don't leave getting diagnosed as long as I did.

Doug