


# Coeliac Disease: A Subtle yet Life Changing Diagnosis

Journal of Patient Experience  
Volume 8: 1-3  
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DOI: 10.1177/2374373521998818  
journals.sagepub.com/home/jpx  


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## Abstract

Coeliac disease is a common autoimmune condition, which may present with a wide variety of extraintestinal symptoms that contribute to a significant delay in disease diagnosis. This personal account, from the perspective of a medical doctor, is an insight into the lived experience of coeliac disease, the process of diagnosis, and the lifestyle changes and challenges associated with the gluten-free diet.

## Keywords

coeliac disease, gluten-free diet, diagnosis, quality of life, atypical, symptoms

## Introduction

Coeliac disease is an autoimmune condition where the small intestine becomes damaged with ingestion of gluten (present in wheat, barley, and rye) (1). Despite it being a common condition with a global prevalence of 1.4% (2), the vast majority of patients remain undiagnosed (3). It is thought that the difficulty in its diagnosis is due to its variable presentation, as not all patients have the classic symptoms like diarrhea or abdominal pain but may solely have extraintestinal symptoms (4). Undiagnosed and untreated coeliac disease is associated with the development of osteoporosis, infertility, further autoimmune conditions, and cancer (5).

I am a patient with coeliac disease and a medical doctor by profession. I was diagnosed only 2 years ago, at the age of 26. Being diagnosed was a eureka moment, to finally obtain a justification for the symptoms that had been plaguing me for over a decade. I wish to detail my symptoms and my feelings while I was unwell, and why my diagnosis took such a long time. I think that medical doctors will find my story interesting and insightful. I also hope that it will be educational and improve their knowledge about the varied presentation of coeliac disease, so that patients like myself can be diagnosed sooner and their lives changed for the better. I also want to share the impact that this diagnosis has had on my life and well-being and how it impacts my work life as a trainee surgeon.

## My Personal Experience of Coeliac Disease

With the gift of hindsight, I realize that my first symptom of coeliac disease was hair loss, starting around the age of 15.

I would wake up in the morning with clumps of hair on my pillow. The shower drain was clogged with hair whenever I washed it. “This was not normal was it? Did I have some kind of nutritional deficiency?” I asked myself. As I was sitting some exams at the time, I attributed this hair loss to stress and was confident it would recover soon.

Two years later, the hair loss was severe. I was at medical school at the time and remember taking some photos with my friends at a party. My scalp was visible in the photos and I looked like someone suffering from female pattern hair loss. I cried in the bathroom that evening. “It must be the stress of medical school that is causing this,” I thought, “maybe I should quit.” In the end, I colored the bald areas of my scalp with a black eyeliner pencil, faked a smile, and rejoined the party. The next day, I bought some nutritional hair growth supplements and was hopeful that it held the answer.

At around the same time, I developed a rash on both my arms that did not disappear with my moisturizing efforts. It was unsightly and hyperpigmented, and I stopped wearing sleeveless dresses or tops so that people wouldn’t see it. I was also significantly fatigued, mustering all my strength to get out of bed on some days. My joints were stiff and

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**Table 1.** Extraintestinal Features of Coeliac Disease (My Particular Symptoms Highlighted in Bold) (6).

Hematological	Dermatological	Musculoskeletal	Oral cavity	Neurological	Reproductive
<b>Anemia</b> Hyposplenism	<b>Dermatitis herpetiformis</b> <b>Alopecia areata</b>	<b>Arthritis/arthralgia</b> Osteoporosis	<b>Aphthous ulcers</b> Dental enamel hypoplasia	<b>Headache</b> Gluten ataxia Peripheral neuropathy	Infertility Miscarriage Intra-uterine growth retardation

aching on some mornings. The nutritional supplements for my hair never worked and I stopped buying them. I felt very low in mood during this time. The extraintestinal features of coeliac disease are summarized in Table 1 (6), with my particular symptoms highlighted in bold.

Some years later, I finally mustered some courage to see my family doctor. He was kind and sympathetic but was suspicious that I might have an underlying autoimmune condition. “Finally,” I thought “I will get an answer for my problems.” My doctor ran a barrage of different tests—for lupus, rheumatoid arthritis, vasculitis and more, but they were all negative. Back to square one I went, defeated and as though I’d wasted my doctor’s time. “This is so embarrassing, they surely must think I have a psychological problem,” I thought. I qualified as a doctor shortly afterward and thereafter was far too busy to worry about my problems again.

## The Journey Toward Diagnosis

One day my mum tagged me in a Facebook article about a patient who had a rash on their arms because of underlying coeliac disease. I cast my mind back medical school. I believe that the entirety of this condition was squeezed onto one PowerPoint slide, and I don’t recall having paid it much attention at the time. I was skeptical that I could have it. Didn’t people with coeliac have abdominal pain and diarrhea? I eat gluten all the time, without any trouble! My doctor was skeptical too but arranged a blood test for me.

I had the shock of my life when my antibody levels were 20 times the upper limit of normal. While awaiting an endoscopy to confirm the diagnosis, I spent much time in denial, “How could I possibly have this horrible condition? How will I find social situations? How could I give up cake? No, surely this is a mistake, I can’t have coeliac disease.”

It was a sobering moment for me when my biopsies confirmed my diagnosis. I remember being upset and mourning the loss of my favorite foods and also feeling grave annoyance at myself for being a doctor and yet not knowing that coeliac disease can have such a variable symptoms.

Having immersed myself in textbooks and literature, I now understood that I had 2 conditions called alopecia areata (hair loss) and dermatitis herpetiformis (rash), recognized manifestations of coeliac disease (4). My gastroenterology doctor thought that the delay in my diagnosis was partially due to my atypical symptoms but also because the appearance of the dermatitis herpetiformis rash can look different

**Table 2.** Gluten-Containing Food Items.

Grains	Beverages	Common food items
Wheat	Beer	Bread
Barley	Ale	Pasta
Rye	Lager	Cereal
Triticale (wheat and rye hybrid)		Cake
		Biscuits
		Pastry
		Sauces
		Sausages

on dark skin (I am Sri Lankan by ethnicity). He also thought that my condition was not so apparent in my childhood because I lived in Sri Lanka as a child, and the diet was almost exclusively rice based. I also personally thought that the fact that coeliac disease is not routinely checked for in patients with autoimmune type symptoms may be a contributory factor.

## The Gluten-Free Diet

The only treatment for coeliac disease is to avoid eating gluten for life by following a strict gluten-free diet. I spent about a week reading about gluten-containing foods and was surprised to find some unsuspecting items were possible sources of gluten—soy sauce, marmite, and even some fruit juices that are flavored with barley. It is also important not to forget that alcohols such as beer also contain gluten. Common gluten-containing foods are summarized in Table 2.

Having gathered the courage to start my gluten diet, I reaped the benefits quickly. Within 2 weeks, I noticed new hair growth on my scalp. Within 8 weeks, the rash disappeared. Within 6 months, my joint pains subsided and within a year, my tiredness was comparable to the normal levels of a junior doctor. Two years later, I have minimal detectable antibodies and a thicker head of hair, which is still recovering.

My top tips for avoiding gluten-containing foods is to meticulously read the ingredient labels on all foods to check for specific mention of wheat, barley, or rye. There are also dedicated gluten-free areas in supermarkets that sell an enormous variety of goods such as bread, pasta, and desserts. It is easy to stay healthy while being gluten free as all fruits and vegetables are naturally gluten free and rice is a healthy grain to substitute for wheat. Therefore, there need not be any worry about nutritional deficiencies.

## The Impact on Lifestyle

Coeliac disease and the gluten-free diet have been a massive lifestyle change, especially for my work life. Prior to my diagnosis, I would buy lunch from the hospital canteen. I then suddenly found that there were no gluten-free options available there or that anything suitable was likely cross contaminated. I suddenly had to become organized—planning shopping trips around my hospital shifts, cooking in bulk, and taking in a packed lunch. Gluten-free food can also be quite expensive—with gluten-free bread, flour, and pasta typically being double or triple the price of their gluten-containing counterparts.

On the occasion if I've forgotten my lunch or I've finished my shift later than expected, I've had to resort to eating boiled potatoes from the canteen, as the only gluten-free item available. The COVID-19 pandemic has also had a big impact on my life. The stockpiling of food also extended to gluten-free good, and on several occasions, I've been to the supermarket to find that there is no rice or gluten-free bread or pasta. Therefore, I've had significant troubles in planning my meals.

I am currently working in general surgery and during long and busy on call shifts, I cannot stay on site in hospital accommodation due to the risk of cross contamination if cooking in communal areas. I find myself commuting 1 hour each way between shifts to my own safe home and clean kitchen, on account of this. I find social gatherings and meals difficult and sometimes awkward, if others want to eat somewhere without a gluten-free menu. On many occasions, I've made excuses not to go, rather than explaining my diagnosis again.

Despite these challenges, my coeliac diagnosis has made me a more diligent doctor. In the time I have been working, I've helped with formal diagnoses of coeliac disease for 2 patients—both incorrectly diagnosed with irritable bowel syndrome. In this way, I am glad that I could have changed 2 people's lives significantly. Interestingly, I have worked with many doctor colleagues, who are surprised that I can have coeliac disease without gastrointestinal symptoms. I now recognize that this must be a gap in medical education because I myself was never aware of this either, prior to my diagnosis.

## Conclusions

I hope that this personal reflection raises awareness of the condition and for readers to understand the emotional and physical toll coeliac disease can have on a person. The main lesson to learn is that coeliac disease may present with non-classical symptoms and for doctors to keep this common diagnosis in mind for patients who have symptoms suggestive of autoimmune disease. I also hope for my colleagues to gain insight into the particular intricacies and challenges of the gluten-free diet, in order to provide more holistic and well-rounded patient care.


## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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