

SIHAM SEMAAN PROFILE



I was born in a traditional Lebanese family where everything rotated around food; Christmas dinners, Sunday lunches, and everyday home cooking. My relationship with food was always a love/hate relationship. I loved food but it always caused me discomfort and pain. In my childhood years, I was always anaemic and the doctors would tell my mom to give me iron supplements, and to feed me spinach and red meat. My teenage years were years of migraines and joint pain. The doctors would attribute that to "part of growing up". I got married in 1987; I was 22 years old; I had my son one year later. In 1992 when I was pregnant with my daughter, my OBGYN said that I would need blood transfusion during delivery because of my severe anaemia. I was sick throughout my pregnancy and I was very weak. Luckily, I had a healthy baby girl, but I lost all my energy after giving birth.

I was 26 years old at the time with a baby and a toddler and feeling like an -80year-old woman. I used to drag myself out of bed in the morning to take care of my kids, and then I would stay in bed as much as possible. I was always depressed and unhappy, always in pain and stressed out.

Years passed and every year I would run all medical tests and lab works. The results were always the same: Severe anaemia without knowing the reason, stomach lining inflammation, and horrible headaches. My nails were brittle and my hair was falling into clumps, but nobody could tell me what was wrong with me.

In 1999, my husband and I met a family doctor in a social event. I don't want to say it was a coincidence, I would rather say it was "God's mercy" to save me from my misery. My husband was chatting with the doctor and briefed him about my condition, so the doctor asked us to visit him in his clinic the second day with my medical file. We did that, and the doctor was looking into my documents with both concern and interest. It was a challenging case for him. He asked for more tests and screenings and asked for one more endoscopy, and my reply was, "but doctor, I've already done two in the last 2 years". He insisted and said that he would go deeper with the scope, down into my "duodenum". I did not understand what he was talking about at the time, but I had no other choice.

I did all the tests and screenings the doctor asked for, and after one week, he called us and asked us to come to his clinic. It was New Year's Eve of the millennium (31st of December 1999). Everybody was getting ready for the party, and I was anxious sitting in the doctor's office waiting for his "verdict". On the way to the clinic, I told my husband "I think I have stomach cancer, but even if I'm diagnosed with cancer, I know now I have a name to my illness."

In his clinic, the doctor welcomed us with a very serious face, and he said, "Well Siham, in all my years as a medical doctor, I haven't met one single patient with your case. I only heard of the disease you have in medical textbooks when I was at medical school. What you have is Celiac Disease or the Sprue"! I did not understand what he was saying, "Celiac Disease" What is that?

Then he continued saying, "Celiac disease is an autoimmune disease that creates a reaction in your body to gluten"... More and more new words, "Celiac, autoimmune, gluten?!?" What is he talking about?

When he saw our perplexed looks, he started to elaborate more on Celiac disease and gluten-free diet.

After couple of hours, we went home, and I felt relaxed and happy for the first time in years. Despite the confusing diagnosis, I had a name to my illness. I know now why I am always sick. I'm not crazy! It's not a psychological illness (as doctors used to tell me). I don't need my anti-depressants anymore!!

However, my life got more complicated. To live on a gluten-free diet in 2000 in Lebanon was not easy. I could not find any gluten-free products at that time; Google was not common, and people would not understand my case, not even the immediate family. "Who has allergy on wheat? People have been eating wheat for thousands of years and nothing happened to them? Why are you different?" those were their questions!

Slowly but surely, I moved on with my gluten-free diet. With my husband's support and my family's care, I was able to regain my energy and started to feel better only few weeks into my gluten-free diet. Everything was better, my mood, my stomach pain, my attitude,... Even my children could feel the change, they were getting to know a new mom, a mom who has energy, who can play with them, laugh with them, study with them, and spend quality time with them. Finally, we had peace at home!

I have been on a gluten-free diet for more than 15 years now, and I had to go dairy-free as well, because of my reaction to Casein, which is a protein found in milk. My body was reacting to casein as it did to gluten before. Therefore, in 2007 I stopped eating all dairy products.

My delayed diagnosis did not pass unnoticed. It left heavy traces on my battered body. My joints, especially my hip joints, paid a heavy price. Unfortunately, when you have one autoimmune disease, your body can develop up to seven other autoimmune diseases at the same time. So I was diagnosed with Rheumatoid Arthritis in 2012. However, with exercise and a healthy diet, I try to maintain a healthy life.

After suffering so much with Celiac and its repercussions, I made it my mission to create awareness about this silent but "wicked" disease. I try to tell each and every person to listen to their bodies and not to ignore the symptoms. Celiac disease has common symptoms like diarrhea, constipation, stomach lining inflammation, vomiting, nausea, anemia, and headaches. However, the subtle symptoms are the tricky ones: joint pains, osteoporosis, palpitations, limb numbness, chills, depression, fatigue, irritability, tooth discoloration, mouth sores, acne flares, ...

Therefore, my mission is clear. My mission is to shed the light on the real meaning of Celiac disease and what it can do to our bodies.

Celiac disease was first described in the second century. Aretaeus of Cappadocia (one of the most famous Greek physicians) wrote a detailed description of an unnamed disease. He described all the symptoms of Celiac disease and he gave the sufferers the name "Coeliac" thus the name is derived from Greek. But the major research for this disease was made in England by Dr. Samuel Gee in 1888. He published the first modern description of Celiac disease. He also theorized the importance of diet in controlling the disease symptoms. Dr Gee used to read old Greek medical books and he referred to the discovery of Aretaeus of Cappadocia. But what Gee missed is the cause of Celiac disease. He thought that the culprit was milk, rice, and different types of vegetables. He even prescribed some toasted bread to his patients! In 1952 a Dutch paediatrician, Dr Willem Karel Dicke was recognized for linking the ingestion of wheat proteins, like gluten, as the cause of Celiac disease.

What is gluten? How does the body react to gluten? The body reacts to gluten, a protein found in wheat, rye, and barley as if it were a poison. The immune system reacts to the protein by destroying the duodenum (a small part of the small intestine responsible for the absorption of vital nutrients from food). The malabsorption leads to serious illnesses. Thus, Celiac disease is an autoimmune disorder. Celiac disease is one of the most common autoimmune diseases. In 1986, it was thought that 1 in 5000 people had Celiac disease. Doctors thought it was a rare condition. Now studies show that Celiac affects 1 in 100 people, and it's also estimated that %83 of people who have Celiac are either undiagnosed or misdiagnosed with other diseases like IBS (irritable bowel syndrome).

What is an autoimmune disorder? An autoimmune disorder occurs when the body's immune system attacks and destroys healthy body tissues or organs by mistake. Autoimmune disorders can also cause abnormal growth of an organ and changes in some organs' functions. There are more than 80 types of autoimmune disorders.

Once a person is diagnosed with one autoimmune disease, he/she can suffer from other autoimmune diseases at the same time. Of the most common autoimmune diseases that come with Celiac are Rheumatoid Arthritis, Crohn's, Lupus, Hashimoto's disease, and Addison's disease.

What is the treatment for Celiac disease? The only treatment for Celiac disease is a gluten-free diet. A person suffering from Celiac cannot eat wheat, barely, and rye. A Celiac patient should also avoid oats unless they are certified gluten-free. Moreover, he should avoid all processed and ready-made foods because they contain gluten in a hidden way. For example, soya sauce has gluten. Processed ham and turkey slices could contain gluten. Liquorice has gluten. Most ice creams have gluten. Some ketchups and HP sauces have gluten. Ready-made salad dressings have gluten. Some store-bought potato chips bags have gluten. Some candy brands have gluten.

How is Celiac disease diagnosed?

There are two ways to diagnose Celiac. Doctors would ask for blood tests to check for anti-bodies. Antibodies are produced in our bodies to destroy foreign substances such as bacteria and viruses. The body produces antibodies as soldiers to fight a specific enemy.

In Celiac disease, the antibodies are attacking a protein that they consider threatening to the body. This protein is GLUTEN. Therefore, if the antibodies are elevated, then it might be Celiac disease. Nevertheless, the most common and most trusted screening is the endoscopic biopsy. The doctor will do an endoscopy. He will use an endoscope (a flexible tube with a light and camera that can screen your digestive tract). Biopsies are collected from the stomach and duodenum and tested in laboratories. If there is partial or total atrophy of the villi in the duodenum, then this confirms the diagnosis of Celiac disease.

Common food allergy tests are not considered a reference to diagnose Celiac.

How to live healthy and happy with Celiac disease? Be very strict with your gluten-free diet. Eat a healthy diet with a variety of fruit and vegetables. Exercise every day to keep your joints in a good shape. Start preparing your own meals. Do your annual blood work to check your iron levels, your calcium, and all the minerals in your body. Follow blogs and websites about Celiac disease and gluten-free cooking. You can find thousands of blogs that offer recipes, articles, and tips about Celiac. Enjoy dining out, but do not forget to mention that you have Celiac disease. In restaurant language, it is called "gluten-allergy".

Just be patient and stick to your diet. It will become a way of life!

Keep in mind that "Feeling healthy and feeling good about yourself is not a luxury. It's an absolute necessity."



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Videos



Mariam TV - 3al Maw3ad *19 August 2016* Celiac Disease: How to Live with it // الجزء الأوّل // 2016 8 الع

https://www.youtube.com/watch?v=30hKNGthalw



الحساسية على أنواع معينة من الطعام وغبرها من الأخبار الثقافية ۲ Celiac Disease: How to Live with it

https://www.youtube.com/watch?v=7mw70w2hnyE



Celiac Disease: How to Live with it شهادة حياة و قصة تعايش مع مرض السيلياك سهام قسطنطين سمعان

https://www.youtube.com/watch?v=aN2BScYKUIE&t=548s

Magazine Articles



AN-NAHAR - Moujtama3ouna 9 August 2016 How did I live with Celiac Disease

http://www.annahar.com/article/444315



The Phucket News - Health Matters *15 February 2015* My life with Celiac Disease

http://www.thephuketnews.com/health-matters-my-life-with-celiac-disease 51013-.php



