Katie: A Patient's Perspective

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It is so difficult to explain how sick I once was. How did it all start? Was it my fault? A year ago these thoughts would have sent me into panic. At that time, the pain was unbearable and the anxiety permeated every aspect of my life. I saw many doctors without benefit, and being desperate and vulnerable, I sometimes took the wrong advice. Thankfully, I did get better and here is how I achieved physical and emotional recovery.

As a child, I was a very picky eater and my early preferences shaped my food choices later in life. In middle school, I felt abnormally full after eating, like trapped air in my belly, with impressive belching. A gastroenterologist ordered a barium x-ray and a food emptying test. While there were no abnormalities, he did say, my digestion was slow, comparable to that of an 80-year-old woman. I was confused by what this meant and what it would mean when I became older. He said I should learn to live with it, which was not reassuring.

By high school, my GI symptoms became more intense. I was often bloated and experienced more frequent constipation and heartburn. I became anxious and the symptoms had a major impact on how I felt physically and emotionally. As a teenager, bloating and constipation meant being gross, unattractive, and fat, so I felt incredibly guilty if I ate and became uncomfortable. A new gastroenterologist assessed my symptoms of fullness, bloating, belching and heartburn, and, after upper endoscopy, said I had mild inflammation in the esophagus and prescribed Nexium. There was no celiac disease. I was to watch what and how much I ate. I was again confused. I saw no connection between my symptoms and the test results. Even after several visits, I felt ashamed to ask questions and felt no rapport with the doctor. Surely, I was wasting his time with silly complaints. He seemed concerned only with the esophagitis; to me that meant that my other symptoms were normal, trivial, or simply untreatable.

My health further deteriorated in college. The new environment meant eating and drinking at all hours, endless amounts of school work, and living with three roommates. My sleep schedule was terrible, my stomach hurt, and my anxiety continued to rise. On a school trip to Puerto Rico, my symptoms flared more than ever: vomiting, diarrhea, and terrible cramping pain. My roommate took me to the emergency room where I was given IV fluids and sent me home. I later learned that this infection may have set the stage for post-infection IBS and dyspepsia.

The rest of that school year was a blur. I frequently passed out and developed persistent headaches. Further lab tests seemed fine, though my blood sugar was elevated. I lost weight even though I was always eating and was always thirsty. My body ached and I became overwhelmingly fatigued. I was soon hospitalized with type I diabetes. The diagnosis gave me an enormous sense of relief. Instead of feeling as if I were complaining, I felt justified for not feeling well.

Having a chronic disease can magnify other underlying psychological issues. My obsessiveness and anxiety made me feel that, if I did not handle this perfectly, terrible things would happen and it would be my fault. I was now convinced that diabetic control would cure my stomach pain, sleep disturbance, and constant fatigue, so I became obsessed with maintaining perfect blood sugars. I thought constantly about diabetes information, my doctor's recommendations, and even magazine articles about "healthy" eating, which kept me further away from the life I wanted.

Unfortunately, diabetic control did not resolve my stomach problems, and the diarrhea, bloating and stomach pain became unbearable. I went to several other gastroenterologists. One told me to increase my Lexapro, which had been prescribed by a psychiatrist for anxiety and depression, but offered no understanding and did not suggest a diagnosis or solution. I felt like such a failure. I refused to go back to this doctor; what was the point? She clearly thought I was crazy or imagining my symptoms.

Another doctor, without looking at my file or asking questions, diagnosed gastroparesis because that was a complication of diabetes. My endocrinologist disagreed as my sugars were controlled and I was diabetic only for a short time. I later learned that though my stomach emptying was slightly slowed, it was not meaningful in terms of my symptoms. Again, I felt vulnerable because two doctors had told me different things and neither helped me feel better.

I sought out naturopathic and homeopathic doctors. They ran expensive food allergy tests and prescribed a lot of supplements and vitamins. They talked about food as poison, and so I began to think about deadly GMOs and evil processed sugars. Gluten and dairy were crimes against humanity. In retrospect, this "healthy"

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and "all natural" approach was far too extreme and limiting, and only made my problems worse. The "healthier" I tried to be, the worse I felt.

So, at 29-years-old, I was living at home, terrified to eat, and unable to work. I watched my friends get married and live their lives, and I could not even go out to eat a meal without having a panic attack. I cried a lot and it always hurt when I ate. I would dream that I was drinking poison, then wake up crying and clutching my stomach. I was so afraid to eat that the weight loss continued and my period stopped. I felt like I had stopped living.

I do not remember what I expected the first time I met Dr Drossman, perhaps it would be similar to my previous doctor visits. What happened was much different. He allowed me to talk and to explain what I thought and how I felt. He did not rush me, and when my voice grew quiet he simply moved his chair closer. After almost 20 years of doctor visits I was finally given a diagnosis: IBS and functional dyspepsia. He explained that those symptoms were caused by overactive nerves in my intestines that worsened after the bowel infection in Puerto Rico. The resultant anxiety and depression created a vicious cycle that made my symptoms worse. Importantly, Dr Drossman told me that this was not my fault. It was not my fault! It was such a relief to hear those words after years of blaming myself for my physical and emotional symptoms.

All this information was hard to take in at once, and I kept asking him to help me distinguish my preconceptions from what was actually true. For instance, it was important to learn that my diabetes and stomach problems were separate conditions; one did not cause the other. Also, my gut was not distinguishing between foods I was eating; I was just feeling those overactive nerves. We talked about different medications that could help and why, the importance of the brain–gut connection, and the value of cognitive behavioral treatment. He reassured me that we had many options to work with, and if one approach did not work we could try another. He said this would be a process and we would work together until I was satisfied. Working together? I had not heard that before! In the end, this understanding of what was going on with my body and what to realistically expect with treatment made all the difference. I left his office and asked my mother whether that really just happened. I was still skeptical, but it helped that Dr Drossman did not promise miracles. He said my stomach would not magically feel better overnight, but it did start to feel better in a few weeks and that was enough for me to keep going.

The medicines made me feel strong enough to begin the psychological work he recommended. With the help of an excellent psychologist, I was able to teach myself how to react differently to the pain, to not feel guilty about eating, and to choose what I wanted to eat instead of what I thought I should eat. With reassurance, it became easier to eat the "evil" gluten, dairy, and sugar. I regained weight and had more energy. The bloating improved and bowel movements became more normal. Then one day, I actually felt calm and relaxed. I started going out with friends again, making plans without becoming anxious. Then finally, I began to work full time, which was so gratifying.

Here is my advice from my experience:

1. Patients must be able to talk to their doctor and feel heard.
2. Doctors should not use complicated and confusing terminology that patients may not understand. From time-to-time, confirm the patient's understanding.
3. Doctors must look at the whole picture, not just the symptoms they are most interested in.
4. A diagnosis with clear explanation of what causes symptoms is vitally important.
5. Doctors should explain why they are prescribing a treatment—especially antidepressants—so that patients do not feel like they are "crazy".
6. Doctors and patients must work together and communicate.
7. The more the patients understand, the more confident and in control they feel, and then they can heal.

I hope that my experience and insight can help doctors and patients to know that there are solutions that really work as long as you work together to find them.

CONFLICT OF INTEREST

The authors declare no conflict of interest.