

The Invisible Disease

By Ryan Twohig



There I was during spirit week at York High School in the fall of 2009. It was a Wednesday in October. I was showing my friend Emily my blue and white outfit for “school colors day”. She caught me starting to smile as she coaxed me into an early-morning photo. It was an awkward location for a photo, in the corner of the cafeteria. There is nothing pleasing to look at in the background. My hat does not match my outfit but I kept it on that day because I felt very cold. I had been having the chills all week. I realize how boring this picture may appear to others, but this bland photograph was the last photo of the first part of my life. The next five weeks would change my life forever. The next day would be the day I would tell my parents how sick I felt. I would tell them I needed to see a doctor. I would explain to them how I had diarrhea and had lost 8 pounds. I would be embarrassed, ashamed, and scared. That picture in the cafeteria holds my innocence. The image is a time before the pills, the hospital, and the absences. It was my last day of school for the next five weeks. Hidden behind my smirk was a tired and weakened spirit. In the next month I would lose twenty pounds. I would go on to be diagnosed with Crohn’s disease. I would not be upset. I would just be relieved to know what I had and begin to be treated for it. Life after school colors day would never be the same.

My story is just one of the stories of the 700,000 Americans living with Crohn’s disease today (CCFA). I am now part of a community of patients that deal with the condition every day of their lives. Crohn’s disease is an inflammatory bowel disease. It is autoimmune based, which means the body’s immune system essentially attacks its own digestive tract. The main symptoms include diarrhea, weight loss, lack of appetite, and abdominal cramps and pain. For the most part, the condition is invisible to those around us. The disease changes not only our personal lives, but also our entire outlook on the way we live. It affects us every single day, whether people know it or not.



After the initial diagnosis, different treatments attempt to bring the patient into “remission”, which is the state at which the disease is under control and the symptoms are not evident. The first time reaching remission is challenging. It is difficult to get better for the first time while realizing that the fight towards wellness is never over, and the fight against the condition is only just beginning. Crohn’s is chronic disease, meaning the patient’s everyday life is altered permanently. As soon as a patient is relatively healthy, they must figure out how to *stay* healthy. Even the simplicities of life begin to take a toll on the patient. Every decision made has an effect on their health, and the burden of these miniscule decisions adds up and become a great weight. A 2009 study concluded that, “despite clinical remission, an important number of CD patients present with anxiety or depressive symptoms”, showing that the burden is not only physical, but mental (Iglesias). Parts of life once taken for granted instantly become choices to be made. In remission, patients may feel and look healthy, but they have to accept that they are not. They always carry an invisible disease.



Even a trip to the grocery store becomes a challenge. Selecting food becomes a slow process, as ingredients must be read and analyzed. We slowly learn what makes us sick and what keeps us healthy, and avoiding “trigger foods” is key. Here, Dr. Frank Sileo, age 41, is making a run to the grocery store. He is choosing a loaf of bread. What appears to be an easy decision has more

significance because of what cannot be seen in the picture. With Crohn's disease he would be asking himself, "Can I eat this food? What are the ingredients? Has this gotten me sick before?". These questions are embedded in the mind of a patient. It becomes a natural instinct, yet the choices are not always simple. Dr. Sileo's basket appears empty, possibly due to a lack of appropriate food at the supermarket. The doctor's current condition may also be affecting his trip. If he is sick, he may be on a more selective diet that requires different food choices than usual. As patients we must learn to deal with temptations. He could be admiring a certain food that he cannot have on his way through the store. A trip that usually requires a quick inventory of the cupboard is often a time of research and analysis for a convalescent.



Thanks to modern medicine, many Crohn's patients are able to remain consistently healthy, but healthy is a term I like to use loosely. I accept that I will never be 100% healthy in my life, but I can reach a respectable level that allows me to live the way I want to. During high school, I was a member of the cross-country and track teams. During my senior year, our team won the indoor track state championship. During our spring season, we again contended for the state championship. We ended up tying our rival, Falmouth, on the final race of the day. I was absolutely thrilled we had won consecutive championships, but deep down I was disappointed with myself. I competed at states in the open 400-meter race. It was my favorite event. I had been having a stressful week and was a bit worried about a flare, but had made it to the day of the meet. I ran the race and placed 8th. I was one place away from scoring. The next runner had only beaten me by .3 seconds. Although not realistic, in my mind I believed those .3 seconds stood between my team tying for the championship or taking it for ourselves. I was upset that I could not contribute to the victory.

Although Crohn's patients can compete and partake in any activity a healthy person can, there always is that lingering feeling of lost potential. The worst question we can ask ourselves is, "What would life be like if I was healthy?" It is simply not who we are and to imagine such a life is only detrimental to the work we have put into recovery. We cannot waste our time imagining something we cannot be. Instead, a patient must be grateful for what they have been given and push their abilities to their fullest potential. Only then may we be truly successful.



One of the biggest stresses for Crohn's patients is not the disease itself, but from the time that it takes to maintain it. When you get a severe flare-up, your life stops. All your energy must be put into getting healthy again. You must work extra hard to treat the condition. The treatment of the flare may be painful, but deep down, you know it is for the better so there is a willingness to do what is necessary. The problem that arises from the treatment is the time it takes. A flare can go on for days, weeks, and sometimes even years. The stress may not come from the disease itself, but from other parts of your life that are lost in the healing process. You may miss work, school, or trips, and society is not going to wait for you. People depend on you and you do not want to let them down. You may need to take care of other obligations even when you really need to care of yourself. It is on your shoulders to make up the work that was missed during your flare up, and it may not always be possible. There are many Crohn's disease foundations and support groups to help you, but they cannot give you back lost time. Life may be even less accommodating for you if you have not told anyone why you are unable to carry on with your routine. The condition is very personal and often time, patients do not like to share it with others unless it is necessary.

For Crohn's patients the disease is invisible, and we like to keep it that way. We do not want it to control our lives. We feel as though not everyone needs to know about our condition, and because of that there is sometimes a lack of sympathy. But we don't need other people's sympathy. Ask any Crohn's patient what they want and they will all tell you that they want to feel "normal" again. Telling people about the condition is detrimental to this hope. I have been fortunate enough to be in remission since May of 2010. My Crohn's may not be severe, but I still deal with it every single day. I am only one of the many people in this community and am so blessed to be able to lead a relatively "normal" life with the condition. It has given me an appreciation of health that I previously never had. Crohn's patients do not want your pity. We want you to understand our aspirations of leading a normal life. So cherish the simple parts of your day, and never take your health for granted. You may not be able to see us, but appreciate that we are in your midst. Our lives with Crohn's bring us challenges, but we carry on. Our condition may be hidden from society, but our motivation and drive to succeed is not.



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