

Patient Stories, continued

The Gastroparesis and Dysmotilities Association
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Calgary, AB

Personal struggles:

It is with relief that I have found this website and tears as I read the personal stories. My case is not as severe but has just as greatly affected my life. My story began in August 2007. I had just finished graduate school, feeling perfectly fine, and the day after graduation I didn't feel well. I thought it was just the summer heat at first.

I wasn't hungry that evening when I had a celebratory dinner with my classmates but I forced myself to eat something because I only had breakfast that day. I stayed up all night feeling so bloated, my chest hurt when I tried to lay down to sleep and I had painful belching.

The next day I was so nauseated at breakfast I couldn't eat and I felt feverish and dizzy. The next two days the symptoms just worsened but I just blamed it on the heat. When I went into work the fourth day, I had very bad pain that was coming in waves over my abdomen and spasms in my chest. The nausea and dizziness was so intense, nothing I have ever experienced before. I had a lunch meeting that day and I couldn't bring myself to eat, I just picked at my salad. When I stood up from the table, I was so lightheaded I fainted.

As soon as I could stand back up, I made my way back to my office but then I had this tightening in my chest. Something wasn't right, this was not normal for me to feel this way so I call my primary doctor and his office told me to go directly to the hospital. I called my parents and drove to their place in Philadelphia and my dad took me to the hospital near their house.

I was admitted to the hospital, I had a fever, they checked my heart and said it was fine. They did an ultrasound on my gallbladder and said it was normal, then they did a CT scan of my abdomen. It showed my appendix was inflamed so they kept me in the hospital. I was there for five days on an IV.

It was my first hospital stay and the most terrifying experience. I was badly treated, the nurses yelling at me as if I was an ignorant child every time the IV failed as if I was making my veins not work and here I was fresh out of school with my MA. I also saw nurses fighting with each other right in front of me on how to get the IV to work, threatening a PICC line until a resident surgeon stepped in. I apparently am also a 'hard stick' and have thin moving veins so the IV kept failing.

My primary doctor visited me and told me they want to keep me because they think I have appendicitis which is why they placed me on the surgical floor. I also learned all the doctors he knew were on vacation so it is just the residents on duty. I had one resident who came in on three different occasions to prep me for surgery. When I asked what they were going to do, she realized she had the wrong patient. Needless to say I did

not sleep my entire time except the two occasions that the nurses knocked me out with a drug so they could 'freely' prick my arms for a new IV.

The two GI doctors that came in to evaluate me just poked at my stomach, just as the residents did on each shift. One of the GI doctor was nicer than the other but told me I was anorexic. I couldn't believe it because at that time I was over weight from being in school the last three years and living on limited income, not so great diet, and free time for exercise was not possible. The other GI doctor decided on doing a colonoscopy to determine if it was my appendix. I had to wait for when they could fit me in.

Once I had the colonoscopy the hospital kicked me out. Literally, the orderly appeared with the wheelchair and a custodian began to clean the room. The doctor and nurses never came in to see me and tell me my test result. After an hour of searching my mother finally got a nurse who turned out to be the nurse manager, she told me that the colonoscopy was normal and I could go. I asked to see the GI doctor, she couldn't find him so one of the residents came in and just said they don't know what is wrong with me so just stay off NSAIDs like Advil.

When I got home I called my primary doctor but didn't hear from him until the next day. I was so scared because I was feeling so awful and in so much pain. When we spoke he told me he went to see me in the hospital that morning and couldn't believe I was discharged against his orders, he had ordered some other test to be done.

He recommended I go to another GI office and called them directly to get me an appointment. I still had to wait five more days. At this point I couldn't eat a thing, I didn't want to drink or eat. I was so weak with dizziness and nausea. The new GI doctor was connected with another hospital. He was very nice, right out of medical school. He ordered some blood tests and scheduled me for an endoscopy for November. I told my primary when I followed up with him a few days later. He wasn't happy and said he would call their office to have it moved up right away.

The following week, it was now September, I was on my way to the emergency room when my primary doctor's office called to say they got me an appointment for the procedure that day. I had the procedure done that day at another hospital. I couldn't believe how nice everyone there was. The doctor prepping me told me I need to ask for the child IV because my veins are very thin, and this time I didn't have that much of a problem with it. They did find I had gastritis in my stomach but the biopsies were normal. I was put on Prevacid.

The next time I saw my primary he wanted me to have some more tests done and said he would discuss it with my GI doctor. I told him how now I was having difficulty swallowing. I had to make a conscience effort to swallow, my mouth wasn't working and when I do swallow the liquid shoots right back into my mouth.

He mentioned I may have a motility issue but first he wanted me to have the gastric emptying scan, which I had in the beginning of October. When I saw the GI doctor, he did not agree with my primary doctor. I don't believe they ever spoke. This became

apparent right away but the GI doctor did order the gallbladder scan with the fatty substance test for the following week but he felt I just had IBS and gave me Levbid that made me very ill. I had the gastric emptying scan and knew right away I failed this test. I was so sick when I had to eat the egg and lay down. I was in so much pain the technician was kind and let me sit up every time the image was taken. I was there for three and half hours and left with the egg only 22% digested.

When my primary called me to tell me I have gastroparesis he told me to immediately stop taking the drug the GI doctor gave me. I finally felt relief to have an answer on what was wrong with me mixed with renewed faith in my primary doctor for ordering this test. Then when I had the gallbladder scan, it didn't go so well. I was in so much pain that lasted for two days after the test. This test showed my gallbladder function was abnormal and I was referred to a surgeon. My primary sent me to a conservative doctor and he did not want to take out my gallbladder to put me at risk of surgery when it may not help what was wrong with my stomach as he thought my gallbladder problem was linked to my stomach problem.

I was put on Reglan which I took for three days. The third day of taking it I blacked out for twelve hours. The GI doctor tried me on a couple more different drugs that were awful. He also ran a lot of different blood tests and I had the upper GI with barium and small bowels test to check for blockage but they were normal.

The GI doctor said I did not exhibit the symptoms for gastroparesis but when I researched online my symptoms match. When I saw my primary in November he suggested I see another GI doctor at another hospital. My primary said he ran out of what he could do for me, he was very understanding to what I was going through, I am grateful for that. He really is a wonderful doctor.

This new GI doctor was his mentor when he was in medical school. I called right away and waited six weeks, just before Christmas, for my appointment with Dr. Cohen at Jefferson Hospital.

What a welcome relief when I met him. He knew all about this illness and understood what I was going through, weight loss of 2-3 sizes, missing days of work, not able to go out with friends and attending social events. He said my case is idiopathic gastroparesis. He mentioned I may have had a viral infection since I had a fever when the symptoms came on. He also asked if I was tested for Lyme disease. I wasn't at the time. I just had the blood work done last week and should get the results this week. He felt that I may get better on my own since it came on so suddenly.

He mentioned the gastric pacemaker but didn't want to go that route as I am young, I am 33, and may get better. What he did suggest was botox injections to my stomach and the opening to my gallbladder. He said it was controversial. That it may not work.

The most frustrating thing is not having anyone to talk to about this illness. Family and friends just don't really understand. I never know how I will feel each day. Today I

couldn't go into work the dizzy and nausea was so bad I didn't sleep and have been having very bad pain.

I am trying to stay positive and hopeful 2008 will be a better year.

Jen in New Jersey.