

Living With Gastroparesis: A Little Hope Goes a Long Way

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Nearly 12 years ago, at the age of 23, I was diagnosed with idiopathic gastroparesis. I had recently graduated from Dartmouth College, an accomplishment that I was especially proud of, given the increasingly severe digestive symptoms that had plagued me since my sophomore year. I had already had my gallbladder removed, consulted several doctors, and undergone many tests; hence, when a gastric emptying scan revealed “markedly delayed gastric emptying,” I was relieved to finally have a diagnosis. It seemed like the first step toward returning a sense of normalcy to my life.

Having left the doctor’s office with little more than the name of the condition and a 3-month follow-up appointment, I scoured the internet in an effort to better understand gastroparesis. At the time, there was not much to be found. What I did find was a message board full of disheartening posts describing symptoms that worsened over time and did not respond to treatment. The sense of relief that came with getting a diagnosis quickly evaporated—nevertheless, my hope for achieving a different outcome remained.

For the next 2 years, I worked closely with my gastroenterologist, trying one treatment after another. We exhausted all of the available medications, plus a few rounds of pyloric Botox injections. Although my diet consisted almost exclusively of applesauce, crackers, and meal replacement drinks, my symptoms were constant. I had lost 40 pounds, had to quit my job, and found myself visiting the Emergency Department every other week.

Feeling rather desperate, I made an appointment with a specialist in functional gastrointestinal disorders. I waited 6 months and drove 4 hours to see him, optimistic that he would have something else to offer in the way of treatment. Our meeting lasted just 5 minutes. After a brief conversation, the doctor concluded, “I have patients much worse off than you. Come back when you need a feeding tube.” The message I heard was There is no hope. There is nothing you can do, and this will only get worse.

For the next few years, that is exactly what happened. Despite trying every conventional and alternative treatment available to me, my physical and mental health continued to decline. I became more symptomatic, malnourished, and desperate than ever. It was

at this point that a doctor suggested I consider having surgery to implant a gastric neurostimulator.

In 2009, after nearly a year of insurance appeals, I had my first gastric neurostimulator implanted at the Mayo Clinic (**Figure 1**). The device provided much-needed symptomatic relief, but, equally important to me, it also provided some much-needed hope. My surgeon was so optimistic, so encouraged that it reignited those feelings in me. This time the message I heard was There is still hope for you. There is more that can be done.

I was not naïve or misinformed. I did not expect the gastric neurostimulator to cure my condition or to eradicate my symptoms.



Figure 1. At the Mayo Clinic, standing beside a sculpture entitled “Hope”.

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Yet, I was once again determined to achieve an outcome different from those I had read about 5 years earlier. The situation no longer felt irreparable. Two weeks after my surgery, I enrolled in a nutrition and health coaching program at the Institute for Integrative Nutrition, once again committed to being a knowledgeable, active participant in my own care.

Six years later, I am now a gastroparesis educator in addition to being a gastroparesis patient. I have had the opportunity to work with hundreds of other people with gastroparesis from around the world and what I have discovered is that my experience is not unique. Patients are eager to commit themselves to their treatment plans, as long as there is an inkling that their effort will make a difference in their outcome. Although I provide information on diet, nutrition, and lifestyle practices to help others manage their symptoms, what they thank me for more than anything, time and time again, is providing them with hope.

I was recently reminded of the importance of this in my own journey when I visited my motility specialist after a particularly frustrating symptom flare. It had been over a decade since I was

diagnosed, far beyond the timeline in my head for possible recovery. The thought of continuing to focus so intently on diet, nutrition, and daily lifestyle practices for the rest of my life had begun to feel exhausting and overwhelming, and hence I had slowly abandoned many of the management strategies that worked so well for me in the past.

Before I left that appointment, I happened to ask whether he thought there was still any chance, after all of these years, that I would get better someday. "I'm an optimist," he said, "I've seen gastroparesis resolve many times. Sometimes slowly, over many years. So, yes. I do think it could happen."

And there it was, exactly what I needed once again... "hope".

CONFLICT OF INTEREST

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