

Life Forever Altered

By Melissa Adams VanHouten

In February 2014, I spent a week in the hospital and was diagnosed with gastroparesis. I am guessing most people have never heard of this; I know I had not, prior to being diagnosed. Gastroparesis means “paralysis of the stomach” and is marked by debilitating symptoms such as nausea, vomiting, stomach and abdominal pain, reflux, early satiety, and severe bloating.

Since diagnosis, my life has been altered in ways I could not have imagined – overnight. One day, I was eating at buffets, and the next day, I was unable to tolerate all foods and liquids. I was hospitalized with severe pain and vomiting, put through a battery of tests (including one particularly terrible one where they forced a tube down my nose and pumped my stomach), diagnosed, and sent home with only a brief explanation of my illness. For the next few weeks, I was on a liquids-only diet and told that I would gradually work up to soft foods and solids. Unfortunately, nothing like that has occurred. I am now able to eat some soft foods, in tiny amounts, but it is clear to me that I will never again be able to eat “normal” foods in “normal” amounts.

At first, I told myself I would not let this disease define or control me – it simply WOULD NOT be the center of my life. But as time passed, I began to see how foolish that was. Every single day, every second of every day, I think about food. I see it, smell it, cook it, and feed it to my family; but I cannot have it. I look in the mirror and see a skeleton. I try to eat even small amounts of food, and I am in agony. I am weak and fatigued to levels I did not think were possible. Some mornings, I do not think I have enough energy to get out of bed. I can barely concentrate and function enough to do everyday tasks. And almost every night, my husband must help me up the stairs to bed because he is afraid I might fall down those stairs. My 13-year-old daughter has seen me vomiting, screaming in pain, lying on the floor crying, and on the verge of passing out. At times, it has frightened her so much that she has asked me to get “Life-Alert.”



I grieve over the fact that I can no longer travel or get out of the house for much of anything – over missing family events, my daughter’s activities, picnics, concerts, and other such functions. I worry that I will not get to see all the significant milestones to come. I am not on the verge of death today (at least I do not think so), but when I look in the mirror, I realize that people like this do not have long lifespans, and it bothers me. I worry about what will happen to my family when I am gone. I fear my daughter’s reaction to my death and the consequences that might result from her growing up without a mother. I want to be there for her when she is sick, scared, or needs advice. I want to see her turn "Sweet Sixteen." I want to hear about her first kiss. I want to see her grow up, graduate, get married, and have children. I want to know that she has a good career and a loving family. I cannot bear thinking about the pain my death will cause my husband, and I am concerned that he might not be able to function when this occurs. I want to grow old with him. Facing the strong possibility that none of these things will occur is anguishing.

I get frustrated because people do not understand how my life is affected by GP. If you saw me on the street, you would likely not realize I am sick. I do not look sick. People frequently ask me if I am better now, and I cannot seem to convince them that I am never going to be "better," not in the sense they mean. I am constantly told I "just need to eat," or that if I would try yogurt, natural herbs, or "get some more rest," I would heal. My own doctor labeled me as anorexic and advised my husband to "watch me." The lack of understanding is incredible, and though I know people mean well, it still bothers me.

I am angry because I am a control freak, and I do not like being a slave to this disease. I do not like being "helped" with everyday tasks and always having to rely on others for aid. I have screamed at, slapped, and pushed my husband away for simply trying to assist me. I have thrown things (including food) across the room in fits of anger. I have intentionally gone without eating – even though I know I should not – just to "show" this disease who is in control. Mostly, I am angry because I do everything I am supposed to do – eat the right foods, exercise, and ingest the known medications – and I am still sick.

There are times when I am in such agony that I can do nothing but cry – lie on the floor and beg God to just let me die. He does not – and I am thankful for that. I think about others who have this disease who are much worse than I am. I know many people who have sought treatment for dehydration, pain, and malnutrition, and who have had to resort to feeding tubes, surgeries, or other extreme measures for nutrition and relief from debilitating symptoms. I sometimes look at them and think that this will surely be my future, too, and it scares me.



I do not understand why I have this disease, and perhaps I never will, but what I do understand is that it is somehow important for me to share my experiences and let others know that despite my challenges, I mostly have a good attitude about my circumstances. In fact, I believe I have been blessed *because of* my illness. Since my initial diagnosis, I have become heavily involved with online gastroparesis support groups and have created and now administer an advocacy group that seeks to foster awareness and change for my community. I feel connected and bonded to others in ways I would have never dreamed possible a few years ago.

I have discovered a whole new purpose and meaning to my life. Over the course of my journey, I have seen unimaginable suffering and need. I am overcome with compassion and concern for the people I have met, and I am likewise overwhelmed by the kindness and support they have shown me over these past few years. I tell you, honestly, every person I know has helped me in some way. They have visited, called, helped with chores and tasks, and simply cheered me up with their stories. Please do not ever be convinced you can do nothing to help or that you do not matter. To those who are struggling, your efforts to understand, your cheerful words, your helpful attitude, and simply your willingness to contribute and be present make all the difference in the world.

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