

# WHAT I'VE LEARNED FROM LOSING MY COLON

BY LOIS FINK

*"The walls of my world gradually closed in until the only place I felt secure was in my own home and in my own bathroom. In an effort to find some humor in what I was going through, I'd joke about my worst nightmare-having to arm wrestle an 80 year-old woman for a vacant bathroom stall."*

Lois Fink is an inspirational speaker who shares her story of courage, "guts," and humor about her 19-year battle with Crohn's disease. Over the years the disease ravaged her colon and rectum. Ostomy surgery, at age 36, gave her back everything Crohn's disease had taken away - a full and active life.

I remember having symptoms of Crohn's disease as early as nine years old. Stomach aches and diarrhea, along with fevers that spiked quickly and left behind shaking chills occurred regularly. In sixth grade, a movie about that 'special time' when girls would become women, captivated me. Hormones would circulate throughout our bodies, we'd experience the first of many menstrual cycles, and our breasts would grow and blossom. My girlfriends bragged about their periods and training bras. I could wear a training bra but there was nothing to train. How could this problem be solved? I realized if I walked slightly hunched over, the front of my blouse or shirtwaist dress would balloon out giving the illusion of breasts. However, this still left the mystery of my delayed menstrual cycle. Though my adored bubbe (Yiddish for grandmother), was deceased, I still felt her presence and shared my hopes and dreams with her every night. I believed in prayer but asking Bubbe for help was not the answer. I needed to direct my pleas directly to God. This was the All Mighty who parted the Red Sea for my ancestors to flee Egypt. Surely a request to jump start my period would be relatively minor on the miracle meter! I prayed nightly and walked hunched over by day. I continued this scenario for months but no breasts filled out my undershirt and no period graced my panties. My mother bribed me to gain weight. "If you get to ninety pounds, you can have that blue mohair sweater your girlfriends are wearing." I wasn't hungry. The abdominal pain seemed worse after every meal. Perhaps if I didn't eat too much, the stomach aches would subside.



In the United States, during the 1960s, doctors made house calls. Every six weeks our family physician concluded that the diarrhea, fever, abdominal pain, and lack of appetite was the 'stomach flu.' He proscribed Phenobarbital for pain. At fifteen, my mother, alarmed at my lack of development, decided action was needed. This took the form of being fitted for a padded bra. I was mortified. The bra, made of rubber, was hard and pointed. I looked in the mirror and nearly cried. I looked like the end of a Red Delicious apple and was sure everyone would know what was underneath my blouse. It reminded me, yet again, how different I was from my girlfriends. At sixteen I saw no sign of menstruation or breast development and so my mother took me to her gynecologist. Afterward he said, "Mrs. Fink, there is nothing wrong with your daughter's birth canal. She will be able to give you grandchildren, but I do not know why her ovaries aren't maturing." Numerous visits to doctors proved pointless. Responses to my lack of growth ranged from 'unknown' to 'growing pains.' Extreme pain in my calves was due to a lack of electrolytes (thanks to severe diarrhea), not from growing.

After a roughly administered sigmoidoscopy by a gastroenterologist he merely labeled me a 'nervous child' and a good candidate for colitis. My mother wanted to believe me but bound by the belief physicians had the answers, doubted my claims. "Lois, I have taken you to numerous doctors and they all say there is nothing physically wrong with you. You've got to get a grip on yourself because if you don't, I'm afraid you will end up in the hospital and it won't

be a normal one. Do you understand what I'm trying to tell you?" I nodded. After she closed the door to my bedroom, I looked into the mirror and repeated her words. I hadn't told her how intense the abdominal pain had become nor how I nearly fainted several times a day in school. As my eyes stared back at me, a small voice in my head protested. "No, I'm not making this up. Something is terribly wrong."

My severe weight loss continued into my senior year of high school. The sight and smell of food nauseated me but I was constantly thirsty. Diarrhea tormented me day and night. I suffered constant pain. I agreed to be seen by one final physician, and while in his office, developed a fever of 102 degrees. "You can't manufacture fevers, Lois. There is something physically wrong and we have to figure this out." "You aren't coming near me," I said.

On a gray February day in my senior year of high school, I climbed the hill to my house, and collapsed in excruciating pain. A mass had developed in the lower right quadrant of my abdomen, I made a detached diagnosis of cancer and concluded I would soon die. A different family doctor examined me and determined I had appendicitis. Stunned, my mother said to the doctor, "You mean my daughter has had appendicitis for nearly two years and the medical profession is just figuring this out?" I was rushed to the hospital and prepped for an emergency appendectomy. I woke up on the

to the frustration was the special diet I had to follow. I craved a normal 'teenager's diet' of pizza, hot dogs, French fries, soda pop, fried chicken, and anything with seeds; everything I couldn't have. I refused to let this diet completely steal time with my friends, and devised a plan. A hamburger bun does have seeds. However, the bottom part of the bun has far less. When going through the line at a favorite 'burger hang-out' with my friend Nancy, I requested two bottom buns. The puzzled cook looked questioningly at me. "I'd like my hamburger on two bottom buns," I repeated nonchalantly. For several seconds we looked at each other. "Give my friend the bottom bun from my order and I'll take her top bun. This way she has two bottoms and I'll have two tops." Nancy leaned over the counter and casually said, "She's secretly into bottoms."

Six months later a bowel resection was deemed necessary. The night before surgery coincided with my high school prom, and my mother expressed sorrow at my missing this event. I resisted saying, "I don't care about the prom and I don't have the boobs to hold up the dress!" After surgery, I gained weight and my delayed physical development rebounded. A year later a major flare occurred, college courses were curtailed and the restrictive diet and steroid therapy resumed.

During the summer of 1975, abdominal pain I'd had for a week, worsened. After several days with no bowel movements, I grew

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Children's Floor of a local Pittsburgh, hospital, and was shocked. I was a sophisticated seventeen-year old. Yes, I looked much younger but that was a minor detail. While reading the Floor Rules a doctor walked in and introduced himself. "Do you want to know what is wrong with you?" he asked. I was frightened, angry, and sarcastic. "Yes," I spat back. "You have Crohn's disease." To my teenage ears, this had to be a disease for really old people. "You also weigh 62 pounds." I spent three weeks in the hospital regaining strength, and wrestling with not being allowed to return to school due to my precarious physical, emotional, and psychological health. Numerous doctors, puzzled by my lack of development, scribbled notes in my chart, and talked as if I wasn't present. I wanted to yell, "I can hear you." "Why me?" I shouted at my father. I didn't think my dad was very smart. A former military man who survived the Invasion of Normandy on Omaha Beach during World War II, he kept most thoughts to himself. "I don't know," he began. He continued, "Perhaps later in life you will meet someone, and because of what you are going through now, you will know what to say and how to help." I stared in disbelief. It would be years before I fully understood the power of my father's answer. They continue to inspire me and maintain a connection with him even though his life ended in 1994. Treatment with Prednisone caused my body to swell with fluid resulting in the classic 'moon face' It seemed overnight, I'd morphed into a chipmunk. As I looked in a mirror at my face, I thought the only things missing were the fur and tail. Adding

concerned. At the end of the work week and halfway through a celebratory meal, my abdomen became distended and hard. The pain steadily worsened and I asked my roommate to get me to the hospital. Doctors admitted me for observation and gave an initial diagnosis as an abdominal abscess. I would need an emergency bowel resection to prevent the bowel from perforating.

Since my first flare up in 1967, Crohn's disease had insidiously tunneled through my colon and rectum. Knowing the exact location of a bathroom wherever I went was crucial. Sitting through a movie or enjoying a meal in a restaurant wasn't possible without running to the restroom. I carried spare underwear because humiliating bowel incontinence was a daily occurrence. One day, while shopping at a trendy department store, I lost control. Keenly aware of the strong odor, I casually walked out of the store as if nothing were out of the ordinary. I fought for emotional control until I reached my car. Tears streamed down my face as I drove home, sitting in a pool of hot, liquid feces, fighting the urge to vomit. It seemed to take forever to get home and even longer to feel clean as I sat crying in a bathtub of hot water. I wrapped up the soiled jeans in a garbage bag and threw them in the trash. I couldn't wear them again. They were too painful a reminder of how Crohn's disease was destroying my body.

At thirty-four, ostomy surgery was recommended, and I recoiled in horror. Bolting from the doctor's office, I spent two years in denial until I realized I was sick of being sick and tired. I made the

decision to have ostomy surgery in 1986. My gastroenterologist told me I needed to meet with one of his patients who had surgery the year prior. After a brief phone conversation with my 'ostomy mentor' we made arrangements to meet at a local restaurant. I arrived early and selected a table where I could see who walked in but at the same time, offered privacy. Knowing what my mentor looked like, helped. Suddenly, a tall, stunning woman wearing a skin tight jumpsuit came in, smiled, walked over, and introduced herself. I'd been staring, eyes scanning her abdominal area. My mother's voice in my head asserted, "Lois, it is not polite to stare at people." I shook my head and nearly muttered, "Not now Ma, I'm busy, and you aren't invited to this meeting." I kept asking myself, "Where's the bag hidden?"

I was free to ask my mentor anything about her surgery, even if I deemed it too personal. What about intimacy? What was it like having a bowel movement through a stoma? Would anyone know I had an ostomy? Would I smell? Two hours later she had an assignment for me. "I want you to list on paper everything you hate about having Crohn's disease. I think this will help you with your decision." She handed me a few sample pouching systems and we scheduled a time to meet at her home. Once home, I shoved the samples under the bed. I wasn't ready to imagine what I would look like with one adhered to my abdomen. I proceeded to tackle my homework assignment and came up with fifteen reasons why I hated Crohn's disease. When I finished writing "I'm tired of being an observer of life and not an active participant," I put the pen

down. Something shifted inside. I could no longer deny how narrow my life had become. Over the years I had changed my life to accommodate a disease that kept me confined to a bathroom, had destroyed my self-confidence, and scarred me internally.

Thirty years ago, in 1986, I checked into the hospital for ostomy surgery. I hung my clothes in the closet and thought, "The next time I wear them, I won't have a colon or rectum." I put on the hospital gown, mismatched bathrobe, climbed into the bed and sat for a long time before going into the bathroom. I disrobed and stared at my body in the mirror. "Take a good look," I said to my reflection. "Starting tomorrow your abdomen will look different. You will have a stoma on the outside your body, covered by an ostomy pouching system." Then I panicked. I grabbed my list of reasons why I hated Crohn's disease and read them over. I looked at my abdomen in the mirror again and at the "X" where the stoma would be and said, "I'm ready."

To say my life after ostomy surgery is 180 degrees better than living with Crohn's disease is an understatement. I am not on medication, or in pain, I have very few dietary restrictions, and don't feel the need to locate a bathroom when out in public. I no longer fear my body will betraying or embarrass me. The sense of freedom is exhilarating. Of course there were hurdles to overcome as I became used to my new normal of having a bowel movement and changing my pouching system. My first accident, due to a compromised seal, rattled my self-confidence, but I learned from the experience. I came to understand the 'ins' and 'outs' of my stoma, which I named my 'side kick.' We have developed a mutual understanding and appreciation of one another. I have discovered distinct advantages in having an ostomy. Our society admires those who can multitask. I can give a talk and have a bowel movement at the same time and no one is the wiser! We are urged to reduce our carbon footprint to protect the environment. Ostomates reduce their 'methane footprint!' We not only pack it in when we hike, but naturally pack it out. The power behind 'projectile poop' is truly amazing. Perhaps we could be consultants for the space program!

Crohn's disease and ostomy surgery have taken me down paths I never would have traveled. They allowed me to discover talents I didn't know I possessed, introduced me to amazing individuals who made a lasting impression on my life. Refusing to take no from the producers at the Sally Jesse Raphael show resulted in a frank discussion about Crohn's disease, ulcerative colitis, and ostomy surgery on national television. I've shared my story with medical and nursing students and practicing nurses. Working with my state representative and testifying before legislative committees, afforded me the opportunity to understand the process by which a bill becomes law. It seemed my father's words were true.

In the middle of a crisis it is difficult to ask what benefits this situation might ultimately bring us, what gifts we might receive if we are willing to see the circumstance in a different light. I am grateful for Crohn's disease and ostomy surgery. The willingness to change how I viewed my situation, enabled me to see my illness and surgery as opportunities for personal growth and development. I no longer resent Crohn's disease or miss my colon and rectum. The gifts I've gained far outweigh their loss.

With my father's words inspiring and guiding me, I remember the past, am grateful for the present, and hopeful for the future. **OC**



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