

Toilet Paper Flowers

A Story for Children About Crohn's Disease



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Coping with Crohn's Disease

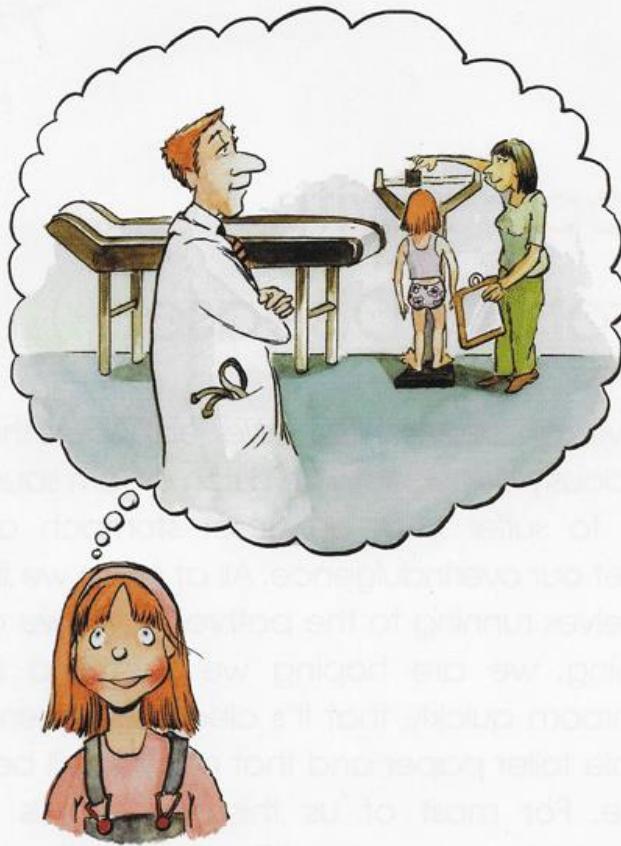
We've all been there—We eat something deliciously decadent with a rich cream sauce, only to suffer from an upset stomach and regret our overindulgence. All at once we find ourselves running to the bathroom. As we are running, we are hoping we can find the bathroom quickly, that it's clean, that there is ample toilet paper and that no one will be in there. For most of us this scenario is an infrequent occurrence, difficult to go through but, once past, it's only an unpleasant memory. However, for those suffering with Crohn's disease, this ritual can be a daily nightmare.

Crohn's disease is one of two types of inflammatory bowel disease. The other is ulcerative colitis. Affecting the gastrointestinal system, these diseases are chronic and painful. According to the Crohn's and Colitis Foundation of America, 1.4 million Americans suffer from these diseases. Of the 1.4 million, 10 percent are diagnosed under the age of 18. Approximately 20 percent of patients

have another family member with Crohn's or colitis. These diseases, which have been identified in infants as young as 18 months, can be difficult to diagnose in children.

The initial symptoms of Crohn's disease may be nonspecific weight loss or delayed growth. Approximately 80 to 90 percent of children with Crohn's disease experience weight loss; 90 percent of children with Crohn's disease experience

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growth failure. Symptoms can range from mild to severe; at times, they can even be life-threatening. Additional symptoms can include any of the following:

- Urgent bowel movements or diarrhea
- Abdominal pain or cramping
- Rectal bleeding
- Low-grade fever
- Inflammation of joints
- Fatigue

- Inflammation of skin and eyes
- Mouth ulcerations
- Delayed sexual development

The causes of Crohn's disease are currently unknown and there is no cure for it. Many of the medications used for the disease only help alleviate inflammation and reduce symptoms or flare-ups. A child who suffers from growth failure may require tube feedings or total

feeding intravenously. In some severe cases, surgery becomes the only option. An estimated 2/3 to 3/4 of children will require one or more operations in their lifetime. I had a 13-year-old male patient who had his entire large intestine removed. Think about that—13 years old, going through puberty and with no colon.

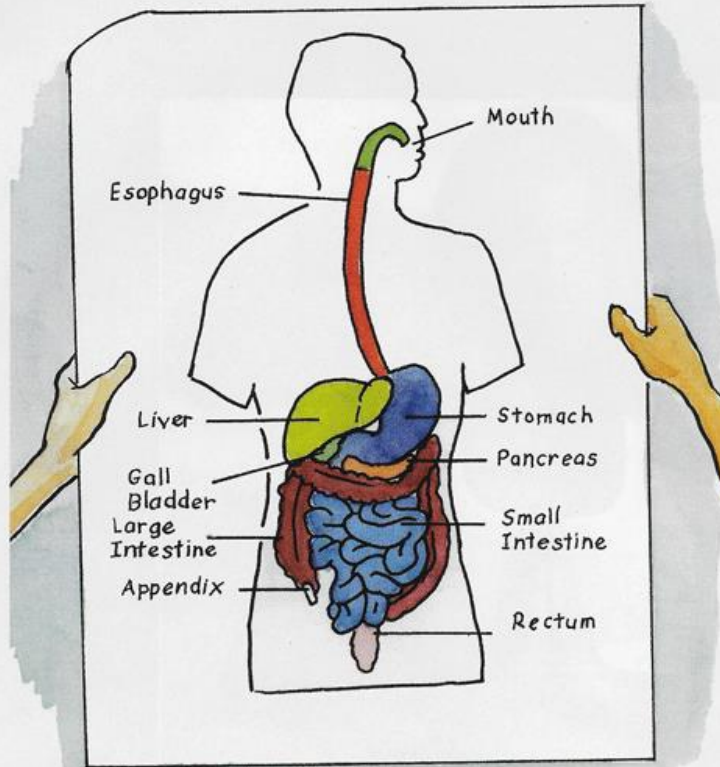
Surgery is not a cure for the disease; it is only part of the care in its management. The surgical procedure involves creating a stoma or ostomy. A stoma is an artificially created opening in the abdominal wall for digested food to empty through. One procedure is called a colostomy and another is an ileostomy; both can provide challenges for adult patients in the areas of intimacy and sexuality.

I have personally struggled with Crohn's disease since 1990. I know firsthand all about the endless medical tests, the interminable waiting in doctor's offices, scheduling appointments, hearing unfamiliar new terms and the score of other challenges. In addition to coping with a chronic illness, there is the balancing act of family, friends and work demands. It can all be overwhelming.

My job as a psychologist requires me to listen to the life problems of my child, adolescent and adult patients. Days when I experience a flare-up are particularly difficult. The hardest but also one of the most rewarding aspects of being a psychologist is working with chronically ill patients, especially children. I am always touched by their hope, perseverance and strength. On the other hand, they come to my office due to feelings of intense guilt. They blame themselves for having the disease. They are frustrated with their bodies. They feel different, inadequate and embarrassed over frequent bathroom use.

Some children express feeling confused because their disease may be overlooked since, at times, they look fine on the outside to others. Inside, however, they feel lousy. Children

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report feeling alienated and isolated, hence some experience depression, anxiety and school problems such as bullying. My job is to help them build on their strengths and to develop a more healthy view of themselves.

My young patients with Crohn's disease may be trying to cope with teasing by peers and pressures in situations involving food and eating. They often have to endure listening to ignorant statements such as "You're so thin. Put a little meat on your bones;" "It's all in your head. You're just stressed out" or my personal favorite, "Gosh, I wish I

had Crohn's disease, then maybe I could lose some weight."

I try to teach patients with a chronic illness to have a "realistic" or "fighting" attitude toward the disease. The fighting attitude teaches that there will be both good and bad days of living with their illness and to find out as much information as they can in order to become an active member of their healing process. Having a chronic illness is like a pebble dropping into a still pond. That pebble sends rippling effects. The pond may include school, work, social activities and the family. Therapy can be

helpful in helping the individual and family deal with the ripples.

In my effort to help children understand the logistics of their disease and to help explore their feelings regarding it, I often employ a technique called bibliotherapy. It involves reading a book related to a specific topic and then discussing with the patient how the characters are dealing with the particular problem. This helps decrease a person's feelings of helplessness and aloneness with a problem. On my bookshelf, I have books related to subjects such as cancer, diabetes and peanut butter allergies. I did a literature search and was unable to find any children's books that addressed Crohn's disease. So I began my journey.

I wrote a book called *Toilet Paper Flowers: A Story for Children with Crohn's Disease*. I found a publisher in New Mexico who publishes children's books on medical illnesses. My publisher—whose sister has Crohn's disease, coincidentally—loved the book and decided to publish it.

The book is the story of a young girl with Crohn's disease and how she explains the disease to her friend. As a way of maintaining hope, she creates flowers out of toilet paper to raise awareness about the disease and to remind herself to stay healthy. The book is intended for children as young as six, but it is also written for parents, siblings and friends of Crohn's sufferers.

For my struggle with Crohn's disease, I turn to my work and this book as my "turning lemons into lemonade" coping mechanism. I wanted to write a story of a child being hopeful despite adversity. That lesson, regardless of struggling with Crohn's disease, is an invaluable one that not only children, but all of us need to learn.

Dr. Frank J. Sileo is a licensed psychologist with a private practice in Ridgewood, NJ. His book *Toilet Paper Flowers: A Story for Children with Crohn's Disease* can be purchased through www.healthpress.com or on Amazon. Dr. Sileo can be reached at (201) 447-0705.