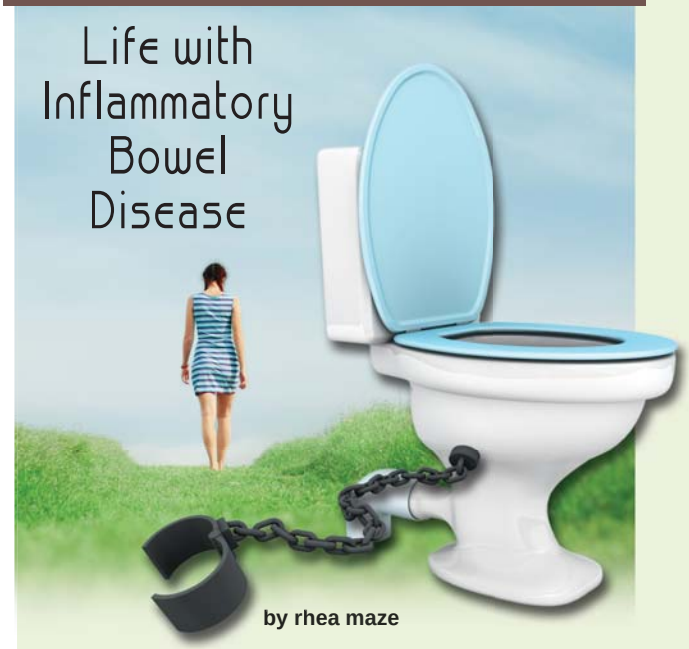
# BEYOND THE BATHROOM

## Life with Inflammatory Bowel Disease



by rhea maze

Seventeen-year-old Lois Fink should have been at prom. Instead, she was in the hospital recovering from emergency surgery and trying to wrap her mind around the diagnosis she'd just received: Crohn's disease. It was 1966, and she'd been rushed to the hospital for an appendectomy during a bout of extreme abdominal pain. But her appendix was fine.

The diagnosis was both frightening and a huge relief. At that point, she weighed 62 pounds and was in constant pain. Her body had not yet developed. She'd been dealing with symptoms including high fevers, pain and chronic diarrhea since the age of nine, yet was misdiagnosed for years.

Crohn's disease chronically inflames various parts of the gastrointestinal (GI) tract and is one of the most common forms of inflammatory bowel disease (IBD). The other most prevalent form of IBD is ulcerative colitis, a chronic disease of the large intestine, or colon, in which the lining of the colon becomes inflamed.

Though Crohn's disease and ulcerative colitis impact the GI tract differently, they share the same hallmark symptoms, including chronic diarrhea that goes on for several weeks, blood in the stool, cramps, constipation, abdominal pain, and sometimes fevers, fatigue and appetite and weight loss.

Though the cause of IBD is not clearly understood, it's defined as an abnormal immune system response in which the immune system mistakenly attacks the GI tract, and it often runs in families. "There's a genetic predisposition, some sort of environmental insult, and then an altered immune response to that insult," says Dr. Mark Gerich, head of the Crohn's and Colitis Center at the University of Colorado Hospital.

Approximately 1.4 million Americans have IBD, including one in 200 college students. IBD can show up at any age yet onset typically occurs between ages 15 and 35.

The standard route to an IBD diagnosis today is a colonoscopy and biopsies. "It's much easier to make an IBD diagnosis now than ever before," Gerich says. "We're looking for it, and finding it, more often."

Fink began aggressive steroid therapy, a restrictive diet and had surgery after her diagnosis yet endured crippling bouts of the disease for the next 17 years. "I felt very isolated and needed to know the location of a bathroom everywhere I went," she says.

Steroids, which can come with harmful side effects and work only for a short time, used to be included in the treatment plans for most people with IBD. Now, a variety of immunosuppressant and non-immunosuppressant medication combinations are being used in addition to a newer class of medications called biologic therapies.

"We think of IBD as a lifelong disease, though it can go into deep remission where medications are stopped altogether," says Dr. Daniel Langer, a gastroenterologist at the Centers for Gastroenterology.

In 1986 at the age of 36, Fink finally consented to an ostomy surgery that completely removed her diseased colon and rectum. An opening created in the abdominal wall allows waste to exit the body via a small pouching system.

"Surgery is an important part of management for a minority of patients," Gerich says. "The vast majority of IBD patients who get surgery are consequently not as sick and their quality of life greatly improves."

Fink was terrified by the idea of ostomy surgery at first. "Then I realized that living in a bathroom stall and watching people's feet go by was no way to live," she says.

Now a patient advocate for the IBD and ostomy community and an inspirational speaker, Fink has been disease-free since her surgery and has a full, active life.

"The key is for patients to diligently monitor their response to therapies," Gerich says. "Not everything works for everyone and it's a matter of finding the right therapeutic regimen for each individual patient."

A great deal of research is currently being done on the underlying mechanisms of IBD and on new treatments in hopes of better understanding and controlling the disease.

"People with IBD should know that it's nothing they did wrong," says Langer. "We still don't fully understand why this disease happens but there are much better treatment options available today that allow people to live productive lives."


## Resources

- If you think you might be suffering from IBD, ask your primary care doctor for an evaluation.
- Learn more about IBD:
  - Crohn's and Colitis Foundation of America, **ccfa.org**
  - United Ostomy Associations of America, **ostomy.org**
  - Get Your Guts in Gear, **igotguts.org**
  - IBD and Ostomy Awareness Ribbon, **igotguts.org/ibdribbon**

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## You're not alone!

The Fort Collins IBD and ostomy support group welcomes anyone experiencing GI-related issues and their families. Meetings typically occur the last Wednesday of the month from 7-9 p.m. in Gifford Hall, room 115. Contact Elise Bascom for more information at ebascom@rams.colostate.edu or Lois Fink at fink.lois@gmail.com.