


# Living with Crohn's Disease

While there is still no cure for the disease, advances in surgery and medical treatments are giving patients a better prognosis.

A young man with short dark hair, wearing a blue button-down shirt, is smiling and looking towards the camera. He is standing in a brightly lit hallway with a wooden desk and a potted plant visible in the background. The lighting is soft and warm, creating a positive atmosphere.

*Christopher Beebe, 24, has a positive outlook after undergoing surgery for Crohn's disease.*

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It is like having your life be uncontrollably steered into oncoming traffic. This is how Christopher Beebe recalls the feeling of being diagnosed with Crohn's disease. "For me, the physical effects of Crohn's disease—ulceration of the intestine, excruciating pain, the impossibility of gaining weight—are infinitely easier to quantify than the emotional effects," says Beebe. "When you think about it, autoimmune diseases are strange in that your body seeks to destroy itself; a contradiction that is hard for the mind to come to terms with."

Now an engineering student—who recently backpacked through seven countries in Europe—24-year-old Beebe looks back on his eight-year battle with Crohn's disease as an experience that made him stronger in the end. While there is still no cure for the disease, advances in surgery and medical treatments are giving patients like Beebe a better prognosis.

## New Medical and Surgical Treatments

It was sophomore year of high school, Beebe remembers, when he began experiencing a mysterious loss of appetite and excruciating abdominal pain. Within months, his weight had plummeted to 120 pounds.

“It was mid-way through my junior year when things got really bad. The abdominal pain had become so severe that I was tired all the time and having trouble keeping up with sports,” he says. “My doctors ran some tests, and that was the first time I found out. At the time, I didn’t even know what Crohn’s was.”

Crohn’s disease is an autoimmune disorder characterized by chronic inflammation of the gastrointestinal tract, which can lead to a breakdown of these tissues and difficulty digesting. “We don’t know exactly what causes Crohn’s disease and we unfortunately do not have a medical or surgical cure. Generally, patients who are symptomatic are treated first with medications, and if complications of the disease occur or symptoms persist, then they will require surgery,” says Patricia L. Roberts, MD, chair, Colon and Rectal Surgery.

The main goal of medication is to suppress the body’s overactive inflammatory response. Traditional medications include anti-inflammatory drugs for mild symptoms and corticosteroids—which nonspecifically suppress the immune system—for moderate to severe cases. The most promising class of drugs, immune modifiers, are helping some patients to maintain remission.

“These newer drugs, which include Remicade (infliximab), act as biological agents. Remicade is actually an antibody that is taken intravenously. In patients with Crohn’s disease who have not responded to any other drug, about two-thirds will see improvement,” says Andrew S. Warner, MD, chair, Gastroenterology, who cared for Beebe.

Despite improvements in medication, about 90 percent of patients with Crohn’s disease will eventually need surgery. This might range from the repair of an intestinal abscess to a more complicated procedure known as resection, during which diseased segments of the bowel are removed and the healthy parts are reconnected. The goal of any surgery is to preserve as much of the gastrointestinal tract as possible.

New, less-invasive surgical procedures include strictureplasty, which enables surgeons to widen narrowed parts of the intestine that are causing obstruction. Because bowel length is preserved, strictureplasty, when viable, is a favorable alternative to resection.

When possible, physicians at Lahey Clinic are performing resection and other surgeries laparoscopically, using tiny instruments and cameras to operate through small incisions.

“In some cases, laparoscopic surgery is not feasible, especially if patients have had previous operations,” says Roberts. “But if it can be performed laparoscopically, patients have smaller incisions, and often less pain and a quicker recovery, which means a quicker return to normal life.”

In certain cases of Crohn’s involving the large intestine, patients may have to undergo removal of the colon and rectum (proctocolectomy), coupled with ileostomy, a procedure during which the small intestine is reattached to an opening in the patient’s abdomen that empties into a small pouch. According to Donna Loehner, RN, who cares for patients who undergo this procedure, the implications of living with an ileostomy are not what they used to be.

“I think ileostomy has a very bad reputation. Years ago, having an ileostomy with

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**The Department of Gastroenterology** at Lahey Clinic has a long history that began with the leadership of Sara Jordan, MD, PhD, who was part of Dr. Frank Lahey’s original team and served on the staff for more than 35 years.

Jordan was known internationally for her pioneer work in the field of gastroenterology, which included the development of comprehensive approaches to treating gastrointestinal disorders, and research into surgical methods for relieving the symptoms of diseases now known as Crohn’s and irritable bowel syndrome.

Mary Stuart Logan, Jordan’s only child, held the Clinic’s mission in high esteem and left a legacy to support the future of medicine at Lahey Clinic. Her legacy was recently fulfilled by her children—MiMi McDougal, Deborah McKenna, Sara Callgren, Donald Logan and Penny Whiton—who gave a generous gift in honor of their mother and grandmother.

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*Donna Loehner, RN, and Kerry Casey, RN, have dedicated their lives to educating and caring for patients who have Crohn’s Disease*



Crohn's disease wasn't the greatest thing because the pouches weren't odor-proof, and they were very uncomfortable to wear. So when people are diagnosed with Crohn's and have to have an ileostomy, it's really the unknown they fear. But today, nothing much changes—they can swim, they can play sports, we are only really changing the way they go to the bathroom.”

Beebe remembers the day that a “freak complication”—a sudden inability to eat or drink—led to his hospitalization. “While they were trying to identify what was wrong, Dr. Warner spent a lot of time with me. He had taken the week off—it was around the Fourth of July weekend—and he still came in every morning, his hair frazzled and all. You could tell he was worried. Both he and Dr. [John] Murray, my surgeon, were with me on a daily basis; they were very dedicated,” says Beebe.

Examinations soon revealed that Crohn's had caused Beebe's stomach and his large intestine to fuse together, blocking off the entrance to his stomach. This complication would require him to have a resection, part of his large intestine and stomach removed, and to undergo an ileostomy. “When told of this, I thought that the rest of my life would be spent dealing with how I was different,” Beebe recalls.

His outlook changed after the surgery, however, when he quickly began regaining his strength. “I always used to say that the best thing about being sick is feeling better, and likewise, the best part about hitting bottom is that you can only rise up. Not long after that, things began to get better. Every day that passed I gained a little more strength back, I could walk a little further, and breathe a little easier,” says Beebe.

## Coping with a Chronic Illness

While some cases of Crohn's disease can be managed through medication or surgery, coping with the chronic disease requires a multidisciplinary approach, where patients meet with specialists from a variety of different disciplines.

Besides being evaluated by a gastroenterologist and colon and rectal surgeon, Lahey patients receive ongoing care from nurses, nutritionists, social services and sometimes physical therapy.

The amount of services that each patient requires is very individual. According to Warner, “What matters is how the patient feels. If you have a patient who is unable to do the usual activities—if they can't go to work, if they can't eat what they want, if they can't take care of their children—that means we need to do more. We target therapy to the patient's quality of life.”

Loehner and her colleague Kerry Casey, RN, have both dedicated their lives to caring for patients who are learning to live with Crohn's disease. “I really enjoy working with these patients. They tend to be a younger population, in their 20s and 30s, and we are often able to help them return to what is sometimes a better quality of life than before,” says Loehner.

“Our surgeons always try to avoid surgery if they can, but those patients who do need surgery come in with a lot of questions,” says Casey. “They often tell us they are concerned about what will happen to them after the surgery. Crohn's disease can go into remission, but it is a chronic illness, and they worry it may not go away.”



*Patricia L. Roberts, MD, chair of Colon and Rectal Surgery, performs both open and laparoscopic surgeries for patients with Crohn's disease.*

Loehner and Casey have found that many patients were enthusiastic about becoming involved with the Ostomy Association of Boston. “They have a registry of patients with similar disease processes, and they send visitors who come to Lahey and meet the patient, and I think it's that camaraderie and that support that uplifts the patient,” says Loehner. “We also arrange family meetings with parents, or a spouse, or anyone interested in learning what the patient is going through.”

“There are tons of people out there with Crohn's disease, but people rarely talk about it,” adds Casey. “It doesn't receive the same amount of press as diseases like cancer.”

The Crohn's and Colitis Foundation of America is busy spearheading a number of research efforts that are leading to a better understanding of Crohn's disease. Recently, a genetic link to Crohn's disease—a mutation in a gene called “NOD2”—was discovered. Scientists believe that abnormalities in this gene may be responsible for the body's inability to “turn off” its inflammatory response, and that genetics is the key to discovering new therapies that could some day lead to a cure.

Since his surgery, Beebe has had no symptoms of Crohn's disease and has returned to an active life of traveling, going to graduate school for engineering, and conducting research in the field of renewable energy. “I'd advise others who are living with Crohn's disease to keep a positive attitude. Everyone gets down if they have a surgery or a colostomy or anything wrong with them, but you have to avoid the pitfalls, like blaming problems on the fact that you have an ileostomy,” he says.

Because of his positive experience, much of Beebe's family have begun coming to Lahey Clinic for their primary care. And Beebe says the few scars he has left are a reminder of his triumph over Crohn's disease: “They are a constant reminder of where I've been, and why it's so important to never forget the most important lesson I've learned: When you're given a second chance, don't look back; you take it and you run.”