Living with Inflammatory Bowel Disease

Understanding IBD
Causes of IBD
Diagnosis & Treatment
Living with IBD
Going to School
Away from Home
At College with IBD
How We Treat IBD
Research
Patient Resources
Understanding IBD

Inflammatory Bowel Disease (IBD) is a term that describes several different conditions that cause inflammation (pain, swelling, irritation and ulcers) in the small or large intestine. Symptoms of the inflammation include vomiting, diarrhea, rectal bleeding and stomach pain. Children with IBD might lose weight or struggle to keep weight on, might feel tired or might not grow as quickly as peers.

The two most common types of IBD are called Crohn’s disease and ulcerative colitis. There are other types of IBD that can be seen in young children as well, including IBD associated with immune deficiency syndromes and IBD seen in transplant patients.

Crohn’s disease usually affects the region where the small and large intestines connect (the last part of the small intestine, or terminal ileum). However, any part of the digestive tract (including the mouth, esophagus, stomach, small intestine, large intestine and anus) can be affected.

Ulcerative colitis also causes intestinal swelling and is usually limited to the inner lining of the large intestine (colon and/or rectum).

Although there is no cure for Crohn’s disease or ulcerative colitis, most patients with this condition can be effectively treated with medications, nutritional therapies and in some cases, surgery.
What causes IBD?

While we do not know the precise cause of inflammatory bowel disease (IBD), we know it is caused by the body’s immune system (the cells of the body that protect against infection) reacting against the patient’s own intestine. This is similar to other diseases caused by a faulty immune system, including asthma, diabetes or rheumatoid arthritis.

Researchers are currently studying the role of genes, environment, diet and intestinal bacteria to identify the causes of IBD.
The first step in treating IBD is to figure out whether or not a patient has Crohn’s disease or ulcerative colitis. To do that, a doctor will take a careful medical history and give the patient a physical exam. Some other tests might also be needed, such as:

- blood tests
- stool samples
- ultrasounds, MRI and other imaging procedures
- endoscopy or colonoscopy

Visit our website for a more detailed look at tests and procedures used to diagnose IBD.

Once a person has been diagnosed with Crohn’s disease or ulcerative colitis, a medical team will find the right kind of treatment for the patient. Typically, this is handled through a combination of medication and a modified diet. In some more serious cases, surgery may be needed to remove or repair a segment of diseased intestine. The majority of IBD patients require medication long-term.

For more information about diet and medications as they relate to IBD, visit the Crohn’s and Colitis Foundation of America.
Living with IBD

While IBD is a serious chronic illness, most people living with the condition have an excellent quality of life. Regular follow-up with your health care providers, proper use of medication and proper nutrition are important, as are a steady routine of exercise and sleep.

As with any chronic illness, having IBD can be stressful, and stress management may help reduce symptoms. For patients with ongoing intestinal symptoms, knowing where nearby restrooms are can reduce stress associated with the condition.

Having the support of a close-knit group of family, friends and your care team is also important, because it helps make IBD symptoms seem less isolating, and dealing with symptoms easier.

To help manage stresses associated with the disease, the Inflammatory Bowel Disease Center at Boston Children’s Hospital includes a team of social workers and psychologists that specialize in children, teens and young adults with chronic gastroenterology illnesses. The team can also offer guidance and support for children with IBD learning to adjust to the stresses of this condition.
Students with IBD may be absent from class for days at a time, might need to make sudden trips to the bathroom, or may have very specific dietary concerns. For these reasons, it’s a good idea for parents or caregivers of children with IBD to set up a meeting with the school’s staff to discuss how the condition impacts day-to-day life at school. Going to school with IBD is very manageable with the support of family, teachers, school nurses and an experienced medical team.

Visit these websites for more information on going to school with:
- Crohn’s disease
- Ulcerative Colitis
Going away from home with IBD

Children and young adults with IBD should feel comfortable traveling away from home. Whether it’s heading out for sleepovers, camp, or traveling for vacation, leaving home can be comfortable for people with IBD, with a few extra precautions.

**Overnight stays**

- Take enough medication with you to last the entire time you will be away.
- If you are on a special diet, bring some snacks and/or food with you from home.
- If possible, let an adult who will be supervising know about your IBD and what it means.

**Travel**

- Talk to a member of your care team about where you are going and for how long, so they can help you plan accordingly.
- Always store medication in carry-on bags in case your luggage is lost.
- Keep medicines in their containers with the original labels.
- Bring along copies of your prescriptions.
- Bring your health care provider’s name, phone number and email address. Try to get the name and phone number of a doctor in the area you’ll be visiting.
Heading off to college with IBD

The first year at college can be stressful for many people, especially if it’s the first time they are managing their health independent of their parents or caregivers. One way to deal with stress is cut out uncertainties. It may help to make a list of potential problems or concerns you have about living at school and then work with a parent, caregiver, friend or medical professional to talk about how to handle them. That way, if problems do arise, they won’t seem so overwhelming. Some things to consider:

- Who will you call in a medical emergency?
- Can you eat the food in the cafeteria?
- Is there a gastroenterologist near your college?
- Will you have a roommate? If so, will you bring up your IBD with him or her?
- Will going off to college affect your insurance plan? If so, how?
The Inflammatory Bowel Disease Center at Boston Children’s is made up of many IBD and child care specialists—each with a unique role in providing care for our patients and their families.

Our entire team is specially trained to make treatment as easy as possible for young patients and their families.

When you make an appointment at Boston Children’s Inflammatory Bowel Disease Center, you and your child have access to a comprehensive care team including:

- Gastroenterologists who are doctors with special training focused on the digestive system and its disorders
- Surgeons who in some cases may need to operate on patients with severe cases of Crohn’s disease and ulcerative colitis
- Nurses to help care for your child and teach you about your child’s illness
IBD treatment continued

With so many experts working together—all with a deep understanding of IBD’s causes, clinical progression and treatment—the team at Boston Children’s is able to properly diagnose and treat patients of all ages. From infants with early-onset IBD to patients entering early adulthood, our team is available to diagnose and treat all types of pediatric IBD, as well as provide consultations for those already diagnosed with the condition but are in need of a second opinion related to diagnosis or treatment.

And because of our center’s size and collective years of experience, the treatment we offer is coordinated quickly and efficiently, getting life back to normal for your child and family as soon as possible.

For more information on how Boston Children’s treats children with IBD, or to speak with one of our IBD specialists, please call us at 617-355-6058 or visit our website at bostonchildrens.org/ibd.
Boston Children’s Hospital doctors and scientists have been leading research to improve the lives of children with IBD. They are currently studying the role of genes, environment, diet and intestinal bacteria to identify the causes of IBD, which will likely lead to better and safer treatments for the condition.

We also have an entire team of doctors and scientists devoted to studying early-onset IBD. Did you know that when children under the age of 5 are diagnosed with the condition they often have different symptoms—and require different treatment—than older children or adults with IBD?

To better understand the mechanics of how early-onset IBD affects the body, researchers at the Inflammatory Bowel Disease Center are actively researching many aspects of the disease, which has led to customized, targeted treatments for patients.

As research in this newer field continues to evolve, Boston Children’s doctors and scientists are confident they will be able to improve diagnostic tests and treatments for the condition, making life with IBD much easier for young children and their families.

Visit our website for more information on our research program.
Visit our Patient Resources page for videos, patient stories and more.