



**CROHN'S
& COLITIS**
FOUNDATION

Crohn's Disease & Ulcerative Colitis:

A Guide for Teachers and
Other School Personnel



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It is important that all students have the opportunity to thrive in an academic environment during their elementary, middle, and high school years. For children with Crohn's disease and ulcerative colitis, this can be a challenge.

That's why it is so important for teachers and other school personnel to understand these chronic intestinal illnesses and the impact they have on young people. Such understanding will help you provide support and encouragement that may influence a child's educational experience, and beyond.

Facts about Crohn's disease and ulcerative colitis

Crohn's disease and ulcerative colitis belong to a group of conditions known as *inflammatory bowel disease* (IBD).

- IBD should not be confused with irritable bowel syndrome (IBS), an unrelated condition that is medically less serious. IBD can be debilitating if not appropriately treated.
- Both Crohn's disease and ulcerative colitis are chronic, or long-term, conditions. The diseases are unpredictable and cyclical. However, most children who have Crohn's disease or ulcerative colitis go on to lead full and productive lives.
- Crohn's disease is a condition in which the walls of the gastrointestinal (GI) tract become irritated, inflamed, and swollen. This inflammation can occur anywhere in the GI tract, including the mouth, esophagus, stomach, small intestine, large intestine (colon), and rectum.

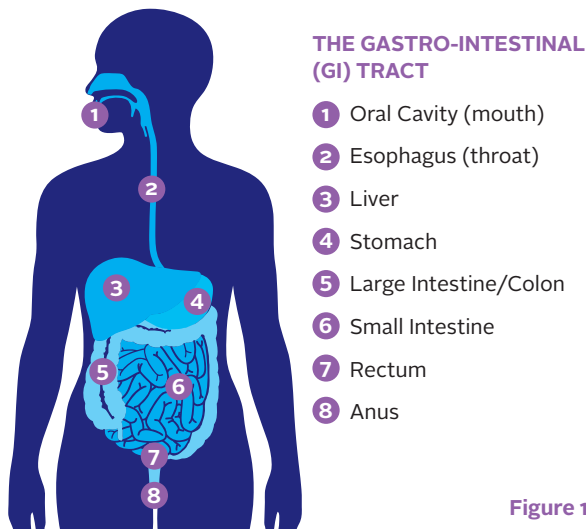


Figure 1

- Ulcerative colitis causes inflammation in the large intestine, or colon, only. Tiny open sores or ulcers form on the surface of the lining, where they bleed.
- More recently, there has been a rise in the number of elementary school age children diagnosed with IBD. You should know that:
 - The illnesses are *not* contagious.
 - Both conditions cause similar symptoms, including:
 - persistent diarrhea (sometimes bloody)
 - fatigue
 - loss of appetite and weight loss
 - crampy abdominal pain
 - intense cramps that can come on without warning, creating sudden urges to use the bathroom. The urgency may be so great that it can result in fecal incontinence (accidental leakage of stool) if there is a delay in reaching the toilet.
- Some adolescents with IBD may have delays in physical growth and puberty, causing them to look younger and smaller than their peers. Many children with these conditions also have joint pain and skin rashes.
- Some young people with Crohn's disease and ulcerative colitis have more chronic pain than others. Chronic pain has been linked to numerous school-related difficulties, including frequent absences, decreased ability to concentrate and perform academically, and impaired ability to cope with the demands of the classroom setting.

Causes and progression of IBD

No one knows for sure what causes Crohn's disease or ulcerative colitis. Researchers believe that IBD is caused by several factors that work together and lead to the development of the disease, including genes, environmental factors or "triggers," and an overactive immune system.

- IBD is not caused by either diet or emotional stress. However, various kinds of stress, such as school exams, may make IBD symptoms worse.
- Symptoms of IBD tend to worsen in an unpredictable manner. This should not be interpreted as a way to avoid school. It is especially important that teachers and other school personnel be available and sensitive to help the student cope during these unpredictable flare-ups of the disease.
- Crohn's disease and ulcerative colitis are lifelong illnesses. Medications can alleviate inflammation and discomfort, but are not cures for the diseases. In addition, many of the medications used can cause unpleasant side effects such as weight gain and mood swings.
- Surgery may be necessary if symptoms and inflammation cannot be controlled by medication alone.

Looking at IBD from the child's perspective

Young people with Crohn's disease or ulcerative colitis say that one of the most difficult challenges in school is their need to use the toilet frequently and without warning due to sudden attacks of pain and diarrhea.

- Children with IBD must be allowed to leave the classroom quickly, without attracting unnecessary attention. Questioning them in

front of classmates about the need to use the toilet may only cause embarrassment and discomfort. In addition, this delay may cause a humiliating accident.

- In some schools, bathrooms are locked for long periods of time for security reasons. Furthermore, toilet stalls may not have doors. Lack of bathroom access can create significant problems for a young person with IBD. Any accommodation the school can provide will be of help.
- One solution may be to provide access to a private bathroom in the nurse's office area or teacher's lounge. It's also a good idea to let younger children store an extra pair of underwear in the nurse's office. Students may be issued a bathroom pass that will guarantee access to restrooms.

Coping

Children cope differently with IBD depending on their age.

- Younger children tend to have a self-image that is still developing, which may help them rebound more quickly from an initial negative reaction to having IBD. They often cope by using avoidance and distraction.
- Middle school kids with IBD may view their illness as a kind of punishment. There can be regression in behavior, with the children acting younger and more immature than their peers. However, most children with IBD tend to try not to draw attention to themselves due to the private nature of the disease.
- Adolescents have a better cognitive ability to understand the illness and its management, but can still be in denial about its seriousness or the need to comply with treatment. In addition, fragile self-esteem associated with puberty can be exacerbated by IBD-related

changes and growth delays. Reactions to the illness can range from denial, grief, and embarrassment to uncertainty and a sense of loss. These, in turn, can lead to alterations in school behavior and functioning.

- The diagnosis of a chronic illness can be difficult for anyone, but for children, it can be especially challenging to process and accept. Young people with IBD are at increased risk of becoming anxious, depressed, frustrated or irritable, less focused, more sluggish, and stressed or overwhelmed. This can occur at the time of diagnosis or later in the course of the illness. Pain and fatigue associated with IBD can interfere with concentration and cause students to withdraw and become angry or have low self-esteem—especially during the pre-adolescent or adolescent years. Additional behavioral transformations that can be seen are extreme mood fluctuations; changes in play, interest, or motivation; and social isolation from peers. Teachers can serve a valuable role as a front-line resource in detecting depression or anxiety in children with IBD.



Social adjustments

Symptoms of IBD and side effects of medications may isolate children and teenagers from their classmates who may or may not be aware of their illness.

- Children with IBD may have different dietary requirements, as eating sometimes causes diarrhea and pain. Children may eat less, or not eat at all, as a way to avoid pain and/or bathroom trips while in school. Not being able to eat in school may contribute to feelings of isolation.
- Medications for IBD can be quite effective in controlling intestinal inflammation and disease symptoms. However, these medications can cause side effects that may include:
 - development of a rounded, puffy appearance (moon face), and weight gain
 - worsening acne
 - mood swings and restlessness
 - sleep disturbance and disruption, which can lead to fatigue and lack of concentration during the school day

Teachers are essential for fostering supportive peer interactions and encouraging children with IBD to stay involved in both their school interests and extracurricular activities.

Taking medication during school hours

Students with IBD often need to take medications during the school day to help control their symptoms. Schools generally require that the school nurse dispense these medications.

- Medication administration by the school nurse should be done in a matter-of-fact, non-judgmental manner. Ideally, arrange-



ments should be made to allow the timely dispensing of medication to a student. These arrangements should ensure that the child not be late for class, or otherwise stand out as being different from their peers.

- In younger children, one strategy might be to combine the visit to the nurse's office with an unrelated task that the child can feel good about (perhaps taking a note or message to the administrative office or serving as hall monitor).
- Adolescents may go through a period of denial, refusing to take their medications altogether. Alerted to this possibility, a teacher or other school professional can step in and help deter potentially harmful behavior.

Absence from school

Children and teenagers with IBD may have to miss school for medical appointments, hospitalizations, or during flares of the disease.

- Not all young people with Crohn's disease or ulcerative colitis show physical side effects of disease or treatment. Although some may appear to be well, they can be quite ill.
- Many kids with IBD may require hospitalization from time to time, sometimes for several weeks. Surgery may be necessary to remove

diseased intestine or to address a complication. While in the hospital, some children may appreciate hearing from classmates and teachers and are often able to keep up with schoolwork. However, it is important to remember that teachers should ask permission before sharing any information with classmates; many students have different preferences.

- Teachers can be instrumental in helping to coordinate an academic make-up plan for school absences with the child, parents, and school counselor. By having a plan in place prior to any absences, getting assignments and class notes and making up exams can be discussed and arranged in advance, subject to school policies.

School accommodations

Two federal laws, Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act, provide protection for public school students with disabilities. Although both laws apply to students with disabilities, not all students with disabilities qualify for the protections of both laws. Each law has specific eligibility requirements and guidelines for services.

- **504 Accommodations Plan:** Also known as the "504 Plan," this law comes from Section 504 of the Rehabilitation Act of 1973. This act requires recipients of federal education funding to provide children with disabilities appropriate educational services designed to meet the individual needs of such students, to the same extent as the needs of students without disabilities are met. A 504 plan spells out the modifications and accommodations that will be needed for these students to have an opportunity to perform at the same level as their peers, and might include such things as an extra set of textbooks or home

instruction. A Section 504 plan involves an evaluation of the child's disability, as well as his or her academic abilities, and specific provisions to help the child reach full academic potential.

- **Individuals with Disabilities Education Act (IDEA):** First passed as the Education for all Handicapped Children Act in 1974, the act governs how states and agencies provide certain educational services to children with disabilities, including children with health impairments like IBD. For students with disabilities who require specialized instruction, IDEA controls the procedural requirements. The IDEA process is more involved than that required under Section 504. One of the provisions of the act requires schools that receive public funding to create an Individualized Education Program (IEP) for each child covered by the plan, ensuring that the unique needs of the child are met in the least restrictive environment. The “individualized” part of an IEP means that the plan has to be tailored specifically to the child's special needs. IDEA covers children with disabilities from birth to age 21.

Accommodations checklist

Students may have different needs for accommodations based on the level of disease activity. If a child is falling behind in school or requires special accommodations to maintain their academic performance, it is important to bring this information to the attention of his or her parents. Informal and formal accommodations may help the child reach and maintain their academic potential. Informal accommodations may be developed by a teacher, parent, and child. Enabling the student to have easy access to an exit might be considered an informal accommodation.

Other strategies, such as “stop the clock” testing, are formal accommodations. Below are some accommodations that might help a student with IBD. Every child may have individualized needs.

- **Unlimited bathroom pass:** Students with active disease symptoms may need to use the bathroom many times per day—often urgently in order to avoid fecal incontinence. Student and teacher should work out an appropriate bathroom signal to help avoid drawing attention to the student's frequent bathroom breaks.
- **“Stop the clock” testing:** When taking an exam, the student may need to take a break due to pain or bowel urgency. Test time will be extended by the amount of time that the student is away from the exam.
- **Ability to hydrate:** Frequent bowel movements and medication contribute to loss of fluids. Students should be allowed to carry and drink fluids throughout the day.
- **Supply bag:** Student will be permitted to eat small snacks and carry candy (to treat dry mouth), wet wipes, and other supplies throughout the day and use as needed.
- **Tests and project limits:** Medications and active disease symptoms may contribute to sleep deprivation and fatigue. As a result, the number of tests and projects can be limited. Test and project deadlines can also be extended without penalty. A discussion between student and teacher can assess individual needs.
- **Rest period:** School nurse will provide a location as needed for students to lie down, or a private place to change clothes.
- **School absence:** After a specified number of days absent from school, the student will receive in-home or hospital tutoring.

- **Alternate seating:** To accommodate easy access to classroom exits, the student's seat may be changed.
- **Medications:** The student, parent, and nurse will meet to discuss and establish a medication schedule.
- **Tutoring and support:** If the student is absent for more than "x" days from school, he/she will have an opportunity to make up or get assistance with assignments. Students will be allowed to have an extra set of books at home.
- **Extracurricular programs:** The student will be allowed to participate in programs and events without penalty due to absenteeism.
- **Physical education class:** The student should be allowed to self-monitor their energy level to determine if they can participate in physical activities. The physical education teacher will notify the parents if there is ongoing non-participation in gym class.

These are some possible accommodations. Others may be added to meet the needs of each student.

Moving on to college

While the IDEA does not apply to post-secondary schools, certain portions of the Rehabilitation Act do. These regulations prohibit discrimination in admissions and recruitment, either by excluding disabled students or by setting a quota for admission of disabled students. A student with a 504 plan in high school can also request accommodations in college.

- Students with health conditions such as Crohn's disease or ulcerative colitis cannot be excluded from any area of campus or academic life to which other students enjoy access, including research, counseling, and occupational training.



- The legislation requires that adjustments be made to eliminate and/or protect against discrimination. These adjustments include everything from extending the length of time permitted for completion of degree requirements, to ensuring that the results of the evaluation reflect the student's performance, not his or her disability. This may include, for example, allowing a student with IBD extra time to complete an exam to allow for bathroom breaks, or a private dorm room.

Participation in physical activities

Young people with IBD should be active and participate in physical activities whenever possible. Generally, there is no reason not to participate in sports, dance, or other physical activities, but some modifications may be necessary if strenuous activities cause fatigue or aggravate abdominal pain, arthritis, or other symptoms. In addition to the physical benefits, including building stronger muscles and bones, these activities provide an outlet for stress and can help build confidence and self-esteem.

Communication with parents and healthcare professionals

Teachers often get to know their students very well. Thus, you may be the first one to recognize when a child is experiencing a flare-up of IBD.

- Some clues might be more frequent trips to the toilet, decreases in food intake during lunch, or a decline in school performance.
- You may be the first to notice indications of a collapse in coping mechanisms. The development of discipline problems or signs of social isolation from peers might suggest such breakdowns.
- Early intervention is important in treating IBD. Timely communication with parents, who can alert healthcare professionals, can be extremely useful in identifying flare-ups or other complications before they progress too far. Additional interventions can then be initiated.

Resources

If you want to learn more about Crohn's disease or ulcerative colitis, or help children and parents learn more, there are a number of resources available to you.

Crohn's & Colitis Foundation website—The website for the Crohn's & Colitis Foundation is home to information on the diseases, their treatments, and brochures, including:

- *Living with Crohn's Disease*
- *Living with Ulcerative Colitis*
- *Managing Flares and Other IBD Symptoms*
- *A Guide for Parents*

- *A Guide for Teens with IBD*
- *Pete Learns All About Crohn's & Colitis: Comic book for kids and teens*
- *IBD & Me: Activity book*

Visit www.crohnscolitisfoundation.org to access these and other resources.

Camp Oasis—The Crohn's & Colitis Foundation Camp Oasis is a co-ed residential camp program. Its mission is to enrich the lives of children with IBD by providing a safe and supportive camp community. For more information, visit www.crohnscolitisfoundation.org or call the IBD Help Center.

Campus Connection—College students can connect with other students and get tips and info at www.crohnscolitisfoundation.org/campus-connection.

Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center)

The IBD Help Center is a free service designed to provide disease-specific information, guidance and support. Our Information Specialists can be reached by calling 888-MY-GUT-PAIN (888-694-8872) Monday through Friday, 9 a.m. to 5 p.m. Eastern Time, or by emailing info@crohnscolitisfoundation.org.

Just Like Me IBD—Kids and teens with IBD have their very own website where they can find specialized information on camps, coping in school, and other helpful tips. You can access the site at www.justlikemeibd.org.

Local education and support programs—Education programs, support groups, and other events are located throughout the country. Go online to www.crohnscolitisfoundation.org to find the local Crohn's & Colitis Foundation chapter in your area.

Other Resources

- **GI Kids (NASPGHAN)**—This website has information about IBD symptoms and diagnosis, treatment and management, coping, and transition. Visit www.gikids.org.

Conclusion

Having a chronic illness is difficult for anyone, but it can be an enormous burden and challenge for children who are in the midst of physical, cognitive, emotional, and social growth. It is vital that teachers and other school personnel recognize the challenge and work toward the goal of providing these young people with a school experience that is as typical as possible.

Education professionals are in a key position to create an environment that fosters resilience in a child or teenager with IBD by:

- Providing opportunities for meaningful participation in academic and extracurricular activities.
- Teaching assertiveness, communication, and problem-solving skills that help the child make sound decisions and effectively manage stress.

People with Crohn's disease and ulcerative colitis have excelled in all fields of life. With the help of an understanding and supportive school system—together with strong parental support and good medical care—it is our hope that all children with IBD will have enriching school experiences and reach their full academic potential.

About the Crohn's & Colitis Foundation

Established in 1967, the Crohn's & Colitis Foundation is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases.

Since our founding, the Foundation has remained at the forefront of research in Crohn's disease and ulcerative colitis. Today, we fund cutting-edge studies at major medical institutions, nurture investigators at the early stages of their careers, and finance underdeveloped areas of research.

In addition, the Crohn's & Colitis Foundation provides a comprehensive series of education programs, printed and online resources, support services and advocacy programs to members of the IBD community, including patients and caregivers.

We can help! Contact us at:

888-MY-GUT-PAIN
(888-694-8872)

info@crohnscolitisfoundation.org
www.crohnscolitisfoundation.org

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The Crohn's & Colitis Foundation is a nonprofit organization that relies on the generosity of private contributions to advance its mission to cure Crohn's disease and ulcerative colitis and to improve the quality of life of children and adults affected by these diseases.