



CROHN'S & COLITIS
FOUNDATION OF AMERICA

Crohn's Disease & Ulcerative Colitis:

A guide for teachers and other school personnel



What's Inside?

Facts about Crohn's disease and ulcerative colitis	2
Causes and progression of IBD	4
Looking at IBD from the child's perspective	5
Coping	6
Social adjustments	8
Taking medication during school hours	9
Absence from school	10
School accommodations	11
Accommodations check list	12
Moving on to college	14
Participation in physical activities	15
Communication with parents and healthcare professionals	16
Resources	17
Conclusion	19
About CCFA	Inside back cover

Wouldn't it be great if all young people could enjoy consistently good health and smooth adjustments during their elementary and high school years? Unfortunately, thriving in the school experience is often a challenge for children with Crohn's disease and ulcerative colitis.

That's why it is so important for teachers and other school personnel to understand these chronic intestinal illnesses. Such understanding will help you provide the support and encouragement that may make all the difference in a child's life.

Facts about Crohn's disease and ulcerative colitis

Approximately 1.4 million adults and children have Crohn's disease or ulcerative colitis.

- Crohn's disease and ulcerative colitis belong to a group of conditions known as *inflammatory bowel diseases* (IBD). These diseases should not be confused with irritable bowel syndrome (IBS), an unrelated condition that is medically less serious.
- Both Crohn's disease and ulcerative colitis are chronic, or long-term, conditions. The diseases are unpredictable and cyclical. Most children who have ulcerative colitis or Crohn's disease 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. See 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 and produce pus and mucus.
- Crohn's disease and ulcerative colitis may occur in children of any age, but the usual onset is between 15 and 25 years of age.

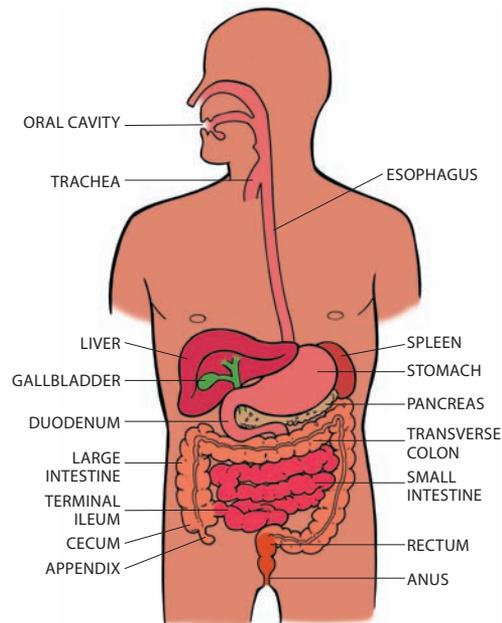


Figure 1

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:
 - 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 or 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

- Researchers believe that IBD is caused by several factors that work together to 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 automatically 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 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 cause unpleasant side effects such as weight gain and mood swings.
- Surgery may be an option 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 their single most difficult problem 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 further embarrassment and discomfort. In addition, this short delay may well 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. You can imagine the problems that lack of bathroom access creates for a young person

with IBD. Any accommodation the school can provide that reduces this anxiety will be of enormous help.

- One answer 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. Middle and senior high school students may be issued a bathroom pass that will guarantee access to restrooms.

Coping

Depending on their age, children cope differently with these chronic intestinal diseases.

- Younger children have a fairly flexible self-image so they can often rebound more quickly from an initial negative reaction to having IBD. They tend to cope by using avoidance and distraction.
- Middle school kids with IBD can have “magical thinking” about the cause of their illness and may view it 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 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, the fragile sense of self-esteem associated with puberty can be exacerbated by IBD-related changes and 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.

- Young people with IBD are at increased risk for depression and anxiety. Depression 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 depressed, angry, or have low self-esteem—especially during the pre-adolescent or adolescent years. Additional behavioral transformations that can be seen with depression 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

As if the attacks of abdominal pain and diarrhea weren't enough to deal with, children and adolescents with IBD often are unable to eat, as eating causes more diarrhea and pain.

Poor dietary intake may slow growth, but not being able to eat in school may further cut off these young people from their classmates.

- Children with IBD may have different dietary requirements. Children may eat less, or not eat at all as a way to avoid pain and/or bathroom trips while in school.
- 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.These side effects and changes in appearance and mood may isolate children and teenagers from their classmates, who may not be aware of their illness and ridicule them.
- 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. Ideally, arrangements 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 and stand out, yet again, as being different.
- 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. Medication administration by the school nurse should be done in a matter-of-fact, non-judgmental manner.



Absence from school

- Not all young people with Crohn's disease or ulcerative colitis are small or show physical side effects of medication. Although some may appear to be well, they can actually 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 alleviate a particular complication. While in the hospital, children 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, important components, such as getting assignments and class notes and making up exams, can be discussed and arranged in advance. It is important that accommodations for each child be coordinated and subjected 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 Plan:** This 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 blood sugar monitoring, 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 his or her academic potential.

- **Individuals with Disabilities Education Act (IDEA):** First passed as the Education for all Handicapped Children Act in 1974 and most recently amended in 2004, 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, the 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 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 IEP means that the plan has to be tailored specifically to your child’s special needs. IDEA covers children with disabilities from birth to age 21.

Accommodations check list

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 the child’s parents. Informal and formal accommodations may help the child reach and keep 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 informal. Other strategies, such as “stop the clock,” are a formal accommodation. Here are some accommodations that might help a student with IBD:

- **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. The student and teacher will 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. Their 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 should be permitted to carry and eat small snacks, 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 to one to two per day. Test and project deadlines can also be extended without penalty.
- **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, they 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.
- **Extra-curricular 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 his/her energy level to determine if he or she can participate in physical activities. The physical education teacher will notify their 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 can also carry over special needs and accommodations to 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 able-bodied 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 or adding time to exams and other evaluation of students to ensure that the results of the evaluation reflect the student's performance, not his or her disability. This may include, for example, allowing an IBD student extra time to complete an exam to allow for bathroom breaks or a private dorm room.

Participation in physical activities

Young people with Crohn's disease or ulcerative colitis should be active and participate in physical activities like sports or dance whenever possible.

Admittedly, some strenuous activities may cause fatigue or aggravate abdominal and joint pain. While a modified gym program may be the answer in some circumstances, it is desirable that the child have some physical activity to maintain good health. 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 health-care professionals

Teachers usually get to know their students very well.

Thus, it is not surprising that you may be the first one to recognize when a child is experiencing a flare-up of IBD.

- Some tip-offs might be more frequent trips to the toilet, decreases in food intake during lunch, or a decline in school performance because of worsening intestinal symptoms.



- Similarly, 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 when problems develop 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 to help.

These include:

CCFA.org—The Web site for the Crohn's and Colitis Foundation of America is home to a great deal of 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*

■ *Pete Learns All About Crohn's & Colitis*

■ *IBD & Me Activity Book*

Local CCFA chapters—Local programs are provided through 12 regional divisions that serve all 50 states and the District of Columbia. To find education programs, support groups, and events in your area, go online to www.ccfa.org/chapters or call the Information Resource Center at CCFA (see below).

Kids and Teens Web site—Kids and teens with IBD have their very own Web site where they can find specialized information on camps, coping in school, and other helpful tips at www.ucandcrohns.org.

Camp Oasis—CCFA 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. Learn more: www.ccfa.org/kidsteens/camp.

Information Resource Center (IRC)—Our Information Specialists offer information through answer chat, phone, and e-mail. They can provide information and educational materials on a variety of topics not discussed in this brochure, such as diet, emotional support, and insurance and financial assistance matters. Information Specialists can be reached at 888.MY.GUT.PAIN (888-694-8872) Monday through Friday, 9 a.m. to 5 p.m., Eastern Time.

Other Resources

- **starbrightworld.org**—An online social network for teens with IBD and serious illnesses.
- **ibdu.org**—IBDU is a resource for teens with information to help them transition from pediatric care to adult care.

Conclusion

Having a chronic illness is difficult for anyone, but for children who are in the midst of growth and development on so many different levels—physical, cognitive, emotional, and social—it can be an *enormous* burden and challenge.

It is vital that teachers and other school personnel recognize that fact and rise to the occasion. Your goal should be to provide these young people with as normal a life in the school setting as possible. Educational professionals are in a key position to provide an environment that fosters resilience in a child or teenager with IBD. You can do so by:

- providing opportunities for meaningful participation in the life of the school.
- teaching assertiveness, communication, and problem-solving skills that will 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 these children will complete their education and make the most of their full academic potential.

This brochure is supported by a grant from the Lisa and Douglas Goldman Fund.



CROHN'S & COLITIS
FOUNDATION OF AMERICA

Attn: Membership
386 Park Avenue South
17th Floor
New York, NY 10016-8804
212.685.3440
www.ccfa.org

The Crohn's & Colitis Foundation of America is a non-profit organization that relies on the generosity of private contributions to advance its mission to find a cure for Crohn's disease and ulcerative colitis.

5/10

