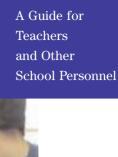




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A Guide for Teachers and Other School Personnel





INTRODUCTION

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 often is quite 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 them provide the support and encouragement that may make all the difference in a child's life. That is the purpose of this brochure.

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). These diseases should not be confused with spastic colitis, which is also called irritable bowel syndrome (an unrelated condition that is medically less serious).
- Both Crohn's disease and ulcerative colitis are chronic, or long-term, conditions. Although they can be controlled with treatment, they cannot be cured. That means the diseases are ongoing, but it does *not* mean they are fatal. They are not. 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. Crohn's may be referred to as *ileitis* when the ileum (lower part of the small intestine) is inflamed; *colitis* when just the colon is involved; and *ileocolitis* when both regions are affected.
- 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 10 and 20 years of age. Both conditions affect males and females equally.
- The illnesses are *not* contagious; one child cannot infect another.
- Both conditions cause similar symptoms: diarrhea (sometimes bloody), fatigue, and

- crampy abdominal pain. Intense cramps 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 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 INFLAMMATORY BOWEL DISEASE

- Researchers believe that IBD is caused by an overactive immune system. Some forms of IBD appear to be linked to genetic abnormalities in certain families.
- 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. But this should not automatically be interpreted as a way to avoid school. It is especially important that teachers and other school personnel be available to help the symptomatic 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 acne.
- Although surgical removal of the entire colon may be curative for ulcerative colitis, symptoms may still recur. Surgery also can create its own set of problems, such as the need for an ileostomy bag or recurrent infections.

LOOKING AT IBD FROM THE CHILD'S PERSPECTIVE

Young people with Crohn's or 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 will 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 or faculty's area. It's also a good idea to let younger children store an extra pair of underwear in the nurse's office.

"Sometimes, when I have to leave the classroom, teachers give me a hard time and I have to explain in front of everybody."

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.
- 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 and grief 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 disorders.
 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 selfesteem—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 force 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 restricted diets (from fiber to a liquid formula nutritional therapy). Teachers and other school professionals need to make sure that kids can eat their special meals without being teased by peers.

Treatment for IBD can cause problems, too.

 Cortisone-type drugs, such as prednisone, are quite effective in controlling intestinal inflammation. However, these drugs typically cause children to gain weight, develop a rounded, puffy appearance (moon face), have worsening

"The hardest thing for me to deal with is the fact that I am different from everybody else. Deep down, I don't want to be different."

acne, and become moody and restless. These changes in appearance and mood may isolate children and teenagers from their classmates, who may not be aware of the illness and may 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 diarrhea, pain, and other symptoms. Schools generally require that the school nurse dispense these medications. Ideally, arrangements should be made to allow the timely dispensing of drugs to an affected student. These arrangements should ensure that the child not be late for class and stand out, yet again, as being different.

- 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 such self-destructive behavior.

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 may 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. Teachers can help enormously by communicating with their pupil's physician or office nurse.
- Teachers can be instrumental in helping to coordinate a 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 balanced with school policies.
- Similarly, if school performance is slipping, teachers should work with the child, parents, and school system to come up with a catch-up plan. This might include supplementary tutoring, some individualized instruction, or a "504-plan" (specifically tailored to help students with special needs feel comfortable within the regular learning environment). Such proactive efforts can help children with IBD develop a sense of accomplishment. They can also decrease the risk of negative attitudes toward school because the child feels ashamed or overwhelmed by poor academic performance.

Most young people — with or without IBD
 — want to keep up with their schoolwork.
 Accordingly, teachers should do everything to optimize in-class catch-up, turning to homeschooling or home-tutoring as last-resort options only.

PARTICIPATION IN SPORTS

Young people with Crohn's disease or ulcerative colitis should be active and participate in sports whenever their illness allows.

Admittedly, some strenuous sports 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 maintain at least some physical activity and not become a "couch potato." Moreover, regular moderate exercise can be beneficial for the immune system.

COMMUNICATION WITH PARENTS AND HEALTHCARE PROFESSIONALS

Teachers usually get to know their students very well. Thus, it is not surprising that they may be the first ones 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, teachers may be the first to notice indications of a collapse in coping mechanisms.

"My teachers think I don't look sick."

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. Thus, 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.
- Direct communication with medical personnel is always valuable if the appropriate consent forms have been signed. For example, it is useful for school personnel to work together with healthcare professionals to determine the appropriate response to pain or appropriate phasing in of physical activities.
- It may be helpful to have the school psychologist or nurse serve as the liaison between the school and the child's medical team.

Physician's name:
Phone number:
Nurse's name:
Phone number:

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 is an *enormous* burden. It is vital that teachers and other school personnel recognize that fact and rise to the occasion. Their 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. They can do so by:

- providing opportunities for meaningful participation in the life of the school; and
- 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 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 potential.



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