



Crohn's and Colitis
Foundation of Canada

Fondation canadienne des
maladies inflammatoires
de l'intestin

Parents, teachers and

INFLAMMATORY

BOWEL

DISEASE



What is Inflammatory Bowel Disease?

Inflammatory bowel disease (IBD) is a term used to describe two similar, yet distinct conditions: Crohn's disease and ulcerative colitis. IBD is also known by other names including: Crohn's colitis, ileitis, distal colitis and pancolitis. These diseases affect the digestive system and cause the intestines to become inflamed, form sores (ulcers), bleed easily, scar and lose the normal smoothness of their inner lining. Symptoms of IBD include abdominal pain, cramping, fatigue and diarrhea.

Crohn's disease can affect any part of the gastrointestinal tract, from the mouth to the anus. Patches of inflammation occur, with healthy tissue between diseased areas; these are called "skip lesions". The inflammation can extend through every layer of affected bowel tissue. Crohn's disease cannot be cured by drugs or surgery, although either or both can relieve the symptoms.

Ulcerative colitis affects *only* the colon (large bowel), and *only* a single layer of bowel tissue: the inner lining. The disease *always* starts in the portion of the colon called the rectum, and *may* extend as a continuous (not patchy) inflammation from there into the rest of the colon. Usually, ulcerative colitis can be controlled with medication. The disease *can* be completely eliminated by surgically removing the colon, but afterward, waste material (stool) may have to be stored and expelled through an external appliance (bag).

No one knows what causes IBD. It affects people regardless of race, gender or age. People are most frequently diagnosed between the ages of 15 to 25 years, or 45 to 55 years.

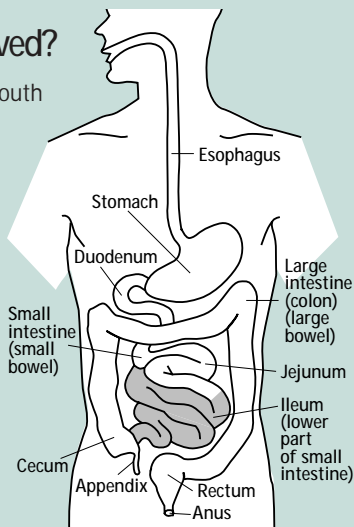
IBD is unpredictable. Many people experience "flare-ups" (attacks) and then the disease seemingly goes away. The quiet periods are called "remission" and can vary in length from weeks to years. Most people will "relapse" and have multiple attacks. IBD symptoms may also vary in severity. Some people have mild symptoms and can be treated with a combination of drugs and nutritional therapy, while others experience debilitating symptoms and need to take potent drugs, visit hospital frequently, and/or have surgery.

See the CCFC brochure "The Facts of Inflammatory Bowel Disease" for more information.

Which Parts of the Body are Involved?

The Digestive System: Food passes from the mouth down the **esophagus** (swallowing tube) into the **stomach**, which dilutes and mixes the food and passes it on to the **small bowel** (small intestine). The small intestine breaks down the food. Each part of the small intestine (which is some six metres long and includes the duodenum, jejunum and ileum) absorbs different nutrients. Leftover material passes into the **large intestine** (also called the **colon** and is about 1.5 metres long), which absorbs water and forms stool. Solid stool is passed to the **rectum** and eliminated through the **anus**.

This brochure is provided for information only. A doctor should always be consulted for advice and medical treatment.



OUR MISSION: FIND THE CURE. YOU CAN HELP. CALL US.
CROHN'S AND COLITIS FOUNDATION OF CANADA
416-920-5035 or 1-800-387-1479

Children, Teens and IBD

Although inflammatory bowel disease (IBD) can develop at any age, it is not unusual for the disease to begin during adolescence, or even in childhood. This brochure is for parents, teachers, and others who may want to know how IBD affects children and how to help them address the issues they face.

Treatment for a child or teenager with IBD is not the same as treatment for an adult. Children have special needs. Important considerations include the fact that: the child is still in his or her growing years, in terms of height, weight and puberty; the child is also not fully mature, socially and emotionally; childhood and adolescence can be a turbulent and confusing time for *any* youngster, and IBD can be an additional disruption.

This brochure deals *specifically* with issues concerning children and adolescents, including:

- signs and symptoms of IBD in children
- medical treatment for IBD in children (nutrition, diet, medication, surgery)
- how the disease affects the child's body, emotions, education, athletic and other interests
- adapting everyday routines to address the needs of the child with IBD.

For a general overview of IBD, read the CCFC brochure "The Facts about Inflammatory Bowel Disease."

Signs, Symptoms and Complications of IBD in Children

MOST SYMPTOMS ARE "INVISIBLE"

IBD is not like the familiar diseases of childhood, such as measles and mumps with their well-known signs of rash and fever. Despite its profound effects, there are few external signals of IBD; in fact, a child or teenager can *appear* perfectly well, when in fact he or she is enduring quite debilitating symptoms. These symptoms may include cramps, abdominal pain, vomiting, fatigue, nausea, and diarrhea. Few of these symptoms are immediately evident to the observer – but they are real, nonetheless.

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To complicate matters, there is no typical IBD patient. The severity of the disease differs from one individual to another. One child may be mildly affected and require minimal treatment; another may be severely affected and require frequent and extensive medical intervention, including hospitalization. IBD is also quite unpredictable. It can flare up suddenly, then be inactive for weeks, months or even years, seeming to have gone away.

Here are some of the symptoms, signs and complications of IBD that pose particular concerns for children and teenagers.

FREQUENT ELIMINATION

For the child or teenager with IBD, diarrhea is perhaps the most embarrassing and disruptive symptom of IBD. The child needs to go to the bathroom frequently, and on short notice. This means frequent wiping of the area around the anus, which could lead to hemorrhoids, abscesses and painful irritation of the skin around the anus.

MALNUTRITION AND MALABSORPTION

Some children come to associate meals, and food in general, with symptoms such as cramps, vomiting and diarrhea. Not surprisingly, meals become something to fear and avoid.

Inadequate nutrition has serious consequences for any growing child, but this is compounded for the child with IBD.

Inadequate nutrition has serious consequences for *any* growing child, but this is compounded for the child with IBD. Not only does the disease interrupt the digestive process, it also interferes with the body's ability to fully absorb nutrients. The dual problems of malnutrition (not enough nutrients) and inflammation will cause the child to lose weight, lack energy, be listless, and lag behind his or her peers in growth and physical maturation.

GROWTH

Children with Crohn's disease – and much less often, those with ulcerative colitis – may not grow as quickly as their peers. This could be simply because the inflammation results in a poor appetite, so the child eats less than is required for normal growth.

Many children have a growth spurt during puberty. In children with Crohn's disease, puberty is delayed. The growth spurt *will* happen, but probably after that of the child's peers. In the meantime, children with IBD may appear younger and smaller than their contemporaries.

Children with IBD may be prescribed glucocorticosteroids to control symptoms. If used over a long time, steroids could stunt a child's growth. The child must be closely monitored by his or her doctor so treatment can be altered as necessary. *See the section "Medication for IBD."*

FATIGUE

When the disease is active, the child may be extremely tired and listless. The child may have difficulty concentrating on schoolwork, chores and other activities. This is not laziness or "acting out."

APPEARANCES CAN BE MISLEADING

Certain medications for IBD (eg, glucocorticosteroids) can make a child *appear* to be in good health when, in fact, he or she is not. Other medications can induce symptoms such as nausea and headaches. *See the section "Medication for IBD."*

Helping Children Cope with IBD

FEARS AND EXPECTATIONS

It can be quite a shock when a child close to you is diagnosed with a chronic, potentially debilitating illness. In some people, IBD can be very serious; in others, it can be relatively mild. Don't assume your youngster is fated to a "worst-case" scenario. Most children lead near-normal lives with the help of treatment that includes medication, nutritional therapy and surgery. For a child with IBD, the future – career, marriage, children – need be no different from anyone else's.

LIVING A NORMAL LIFE

Some children suffer relatively mild symptoms of IBD. With treatment, they get better easily, and stay well for weeks, months, even years, before the disease flares up. Other children may contend with ongoing inflammation and debilitating symptoms. However severe their disease, children usually respond well when they are allowed to be "just like the other kids." Unless they are quite unwell, they should be encouraged to go to school, participate in appropriate hobbies and sports, take music lessons – do all the things their friends do. In between flare-ups of the disease, children can live quite normal lives.

ATTITUDES AND EMOTIONS

“Having a bowel problem” is embarrassing in our society. It can be difficult for anyone – adult or child – to accept. Being “different” can have a profound impact on a child’s self-concept, body image and lifestyle. He or she may rebel or deny they are ill, and avoid or refuse treatment. It may be difficult for adults to remember this person is, after all, still a child. You can help the child adjust to life with IBD. Learn about these diseases. Share your knowledge with the child. Be accepting and supportive. If you are matter-of-fact about its symptoms and treatment, the child will be too.

Being “different” can have a profound impact on a child’s self-concept, body image and lifestyle.

Provide the child with a copy of the CCFC brochure “Kids and Inflammatory Bowel Disease.”

Medical Treatment for Children with IBD

NUTRITIONAL TREATMENTS

There is no special diet for IBD. When a diagnosis of IBD is made, the child’s health-care team - which may include a gastroenterologist, family doctor, nurse, dietitian and others – will advise the child and parents about appropriate nutritional supplements and alternatives.

From time to time, certain diets (low-fibre, high-fibre, low-sugar, dairy-free) become “all the rage,” but none has proven to have real benefits.

Balanced Meals: Children with IBD eat pretty much the same foods as other children: a blend of carbohydrates, proteins and fats.

Some Foods Cause Problems: Certain foods can cause symptoms, such as cramps and excess gas. Looser stools may result from eating sugary desserts, soft drinks and undiluted fruit juices. Limiting or eliminating the foods that cause symptoms will reduce symptoms but certainly won’t cure the disease.

Lactose Intolerance: In addition to IBD, the child may also be lacking lactase, the enzyme that digests lactose (a sugar found in milk and milk products). Growing children need the vitamins and minerals (such as calcium) that milk products provide, but if they’re lactose intolerant, these foods will cause cramps and diarrhea. Children may have to avoid certain milk products, including ice cream. Other alternatives include: drinking low-lactose or lactose-treated milk products or taking lactose tablets before having milk and milk products. Lactose tablets are available without a prescription.

Nutrition Without Food: Sometimes, children with IBD may need to take nutrition in an alternate form because they are too ill to eat properly; or their health care team may recommend that the bowel “have a rest;” or they may not be deriving sufficient nutrition from the usual sources.

One way children can get the nutrition they need is from a pre-prepared or “elemental” diet in which carbohydrates, proteins and fats have already been pre-digested. The nutrition can be delivered orally, but it’s not very pleasant

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tasting, and may instead be delivered through a naso-gastric (NG) tube. A pump delivers the liquid to the stomach by means of the tube, which is passed through the nostril to the stomach. NG tube feeding may be prescribed to pre-teenage children, to help them gain weight and grow. A course of treatment may last a month or longer. The parent and/or child can learn the techniques involved, so NG feeding can be done at home, rather than in hospital. The child may want to remove the tube each

morning and replace it at night, or may prefer to keep the tube intact until the course of treatment ends.

When other forms of nutrition fail or are inadequate, a child may need total parenteral nutrition (TPN), in which he or she is fed intravenously. This used to be done almost exclusively in hospital, but is now becoming a technique that can be administered at home.

For more information, see the CCFC brochure “Nutrition, Diet and Inflammatory Bowel Disease.”

Medication for IBD

The primary purpose of medication is to control inflammation in the bowel so that pain and other symptoms are reduced. The child will feel better, grow and develop normally, and enjoy life. Some medications treat the inflammation itself. Others treat complications arising from the disease. Medications may include anti-inflammatories, antibiotics, immunosuppressives, pain killers, and supplemental vitamins and minerals.

What parents and other adults should know about medications:

Taking Medication: Most medications are taken orally. Others are taken in enema or suppository form. Some – particularly for ulcerative colitis, which affects the lowermost portions of the digestive tract – are *only* effective in enema or suppository form.

Reactions to Medication: Any drug can cause a reaction in some users. A commonly-prescribed anti-inflammatory drug, sulfasalazine, can also cause such allergic reactions, which include rashes and fevers. Non-allergic reactions include upset stomach and headaches. There are alternatives to sulfasalazine.

Glucocorticosteroids: Some children are prescribed glucocorticosteroids to reduce inflammation. These are very powerful drugs. They should not be confused with sex hormones, or with the anabolic steroids used by athletes to improve performance.

Steroids can make a child appear healthier and induce weight gain, but can also cause appearance-related side effects.

Steroids will actually make the child appear healthier and induce weight gain, but they can also cause acne, facial hair and a rounded or moon-faced appearance. Steroids may also impair growth, delay puberty and cause mood changes.

A course of steroids is taken over several months and must be tapered off gradually; they should *never* be stopped suddenly.

Common Painkillers: Children and teens with IBD should *not* take the common painkiller ASA (acetyl-salicylic acid) for headaches. ASA aggravates stomach and duodenal ulcers and bleeding of inflamed tissue.

SOME COMMONLY-PRESCRIBED MEDICATIONS

Medication to Treat...	Generic Name
Active Crohn's Disease	Sulfasalazine 5-ASA Glucocorticosteroids Metronidazole
Crohn's Disease in Remission	Sulfasalazine 5-ASA Glucocorticosteroids (on alternate days) 6MP or Azathioprine
Active Ulcerative Colitis	Sulfasalazine 5-ASA 5-ASA enemas Glucocorticosteroids Corticosteroid enemas
Ulcerative Colitis in Remission	Sulfasalazine 5-ASA

For information on specific medications, see the CCFC brochure "Medication for Inflammatory Bowel Disease."

Surgery for IBD

Surgery is not an uncommon treatment for IBD. In Crohn's disease, surgery won't cure the disease; it's done to relieve symptoms. In ulcerative colitis, surgery cures the disease by removing all the diseased tissue. After surgery, the person may require artificial devices to store and eliminate stool. *The many surgical options are discussed in detail in the CCFC brochure "Surgery for Inflammatory Bowel Disease."*

Surgery for Children with Crohn's Disease: Crohn's disease can result in abscesses (infected boils) and fistulas (openings from the bowel to other organs, or to the skin). Surgery usually repairs these problems.

As Crohn's disease progresses, the bowel, which has a tube-like structure, may thicken. This narrows the bowel's passageway. Eventually, inflammation causes fluids and other materials to block up within the bowel. Surgery (strictureplasty) can remove the obstruction and widen the bowel.

In another form of surgery, resection, a diseased portion of bowel is removed and the two remaining healthy ends are joined together. The inflammation may recur in the same place.

Diet after Surgery for Crohn's Disease: A child with active Crohn's disease, or who has had surgery to remove diseased portions of the small bowel, has less tissue to absorb the fat in food. He or she may need a low-fat diet.

Surgery for Ulcerative Colitis: Ulcerative colitis affects *only* the colon (and *always* the part of the colon called the rectum). Surgery isn't as common a treatment for ulcerative colitis as it is for Crohn's disease. Surgery cures ulcerative colitis by removing most, or all, of the colon (the large bowel). Surgery is usually done in two or three stages, with several weeks between stages to allow healing. Over time, the remaining small bowel adapts to take over most of the functions of the colon. However, the person may have to wear ostomy "appliances," temporarily or permanently, to store and eliminate stool. He or she may have frequent, urgent bowel movements and little or no control over them.

It may be important to reassure children that ostomy appliances don't show through clothing.

An ostomy can be quite an adjustment for children and teens, who are already extremely conscious of their bodies. They may feel uncomfortable using public washrooms, changing clothes, taking gym classes and participating in sports. It may be important to reassure children that ostomy appliances don't show through clothing, and that urination isn't affected by this surgery – only bowel movements.

Parents: Helping Your Child at School

School is central to the life of any child or teenager. A child with IBD needs reassurance. Adults can reinforce a child's confidence by being matter-of-fact about meeting their needs.

The school nurse can be a parent's best ally in ensuring other school staff understand the nature of the disease.

Inform the School Your Child Has IBD: The appropriate school authorities should be informed as soon as a diagnosis of IBD is made.

The school nurse can be a parent's best ally in ensuring other school staff understand the nature of the disease. Parents should talk to their child's current teacher (and every year after, with the new teacher). Give them a copy of this brochure. Make arrangements for washroom breaks, absences from school, homework, school trips, and so on.

Make Arrangements for Day-to-Day Needs: Work with your child to ensure his or her school lunches are balanced (and eaten!). Let the school know if your child requires naso-gastric tube feeding at school, or if your child is wearing such a tube.

Absences from School: A child with IBD may be unable to attend school for extended periods, such as when the disease is active, or hospitalization is necessary. Discuss flexible homework arrangements with the child's teacher. Make sure the teacher knows well in advance about appointments for clinic visits.

Taking Medication: The school may have a policy about carrying and storing medication. Younger children may be expected to report to the school nurse to ensure medication is taken regularly. Older children and teenagers might prefer to be responsible for their own arrangements.

Teachers: Helping the Student with IBD

Understand that when your student is ill, it's not always obvious. Also, an ill student may have trouble concentrating on his or her class work.

Washroom Breaks: Diarrhea and an urgent need to go to the bathroom (sometimes prompted by the phenomenon known as “false urges”) are an inevitable reality for people with IBD. For children and teens, it's important to minimize the embarrassment of being “different.” Allow your student to go to the washroom as frequently as needed, and seat your student by the classroom door so he or she can leave as unobtrusively as possible.

Punctuality: IBD knows no timetable and attacks don't happen on cue. Your student may be late for class.

Absences from Class: Your student has a chronic disease. Illness, clinic visits and hospitalization are inevitable aspects of his or her life. Be flexible about learning schedules and deadlines. Talk to the student, and parents, about lesson planning and homework the student can do while away from class.

Class Trips: Field trips can be problematic for a student with IBD, due to limited washroom facilities. Your student may have to be excused from some of these activities, especially when the disease is active.

Strenuous physical activities may need to be modified for the student with IBD.

Physical Education Classes and Sports: At times, strenuous physical activities may need to be modified for the student with IBD. Make these decisions in consultation with the student, his or her parents, and the student's health care team.

A Change of Clothes: Accidents happen. Children should have a change of clothes stored at the school (teens can keep theirs in their locker). Notes on medication should be kept handy, as should a list of emergency contact names and numbers. It might be a good idea for the child or teen to wear a medical alert bracelet or necklace.

What to Tell Classmates: Take your cue from the student about how to treat him or her. He or she may want to make a class presentation explaining IBD to classmates. Alternatively, he or she may prefer to keep the matter private.

Standards of Behavior and Academic Achievement: As a teacher, you have certain expectations of your students in terms of how they behave and how they perform scholastically. Your standards need be no different for the student with IBD than it is for the rest of your class.

More on Encouraging the Child with IBD

Children with IBD may sometimes have pain from abdominal cramps. They may go to the bathroom dozens of times a day and through the night.

They may be physically weakened and tire easily. This may rule out certain contact sports and physically-demanding activities. Illness may make them absent from school and other activities for long periods of time. Clinic visits and hospitalization may become as much a part of the routine of their lives as piano lessons and softball practice.

For children with IBD, clinic visits and hospitalization may become as much a part of their daily routine as piano lessons and softball practice.

Nevertheless, it's important that children with IBD be offered appropriate opportunities to participate in activities; they should not only be allowed, but *expected*, to contribute to their community. As an adult who is part of the life of a child with IBD, you exercise tremendous influence over the child's perceptions and acceptance of this chronic disease. Your positive, supportive attitude can help them come to a realization that life is about so much more than their illness.

Notes:

Together, We Can Find the Cure

The Crohn's and Colitis Foundation of Canada (CCFC) is a not-for-profit voluntary medical research foundation. Our mission: To find the cure for Crohn's disease and ulcerative colitis. To realize this, the CCFC is committed, first and foremost, to raising funds for medical research. The CCFC also believes it is important to make all people with inflammatory bowel disease aware of the Foundation, and to educate these individuals, their families, health professionals and the public about these diseases.

**YES! I support the search for the cure for IBD.
Here is my tax-deductible donation right now for:**

\$35 \$50 \$100 Other: \$ _____

I prefer to contribute by: Cheque MasterCard
 VISA AMEX

Card Number: _____ Expiry Date: _____

My Signature: _____

Name: _____

Address: _____

Postal Code: _____ Telephone: _____

Please send me details about:

- contributing monthly to the search for the cure
(the Dedicated Research Donor program)
- volunteering my time and skills to the Foundation
- corporate sponsorship of the CCFC and its programs
- including the CCFC in my will
- membership in the CCFC
- Je désire recevoir la documentation en français.

Please make cheques payable to: The Crohn's and Colitis Foundation of Canada. Send your cheque and this form to the CCFC National Office, 21 St. Clair Avenue East, Suite 301, Toronto, Ontario M4T 1L9. For more information on activities in your area, please visit our web site at www.ccfc.ca or contact your Regional Office listed on the next page.

Crohn's and Colitis Foundation of Canada

NATIONAL OFFICE

600 - 60 St. Clair Avenue East
Toronto, Ontario M4T 1N5
Telephone: (416) 920-5035 or 1-800-387-1479
Fax: (416) 929-0364
Web site: www.ccfc.ca
E-mail Address: ccfc@ccfc.ca

REGIONAL OFFICES

British Columbia/Yukon Territory

Telephone: (604) 685-1844

Alberta/Northwest Territories

Telephone: (403) 569-8477

Manitoba/Saskatchewan

Telephone: (204) 231-2115

Ontario

Telephone: (416) 920-5055

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Telephone: (514) 342-0666

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Telephone: (902) 422-8137

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