



Crohn's and Colitis
Foundation of Canada

Fondation canadienne des
maladies inflammatoires
de l'intestin

SMOOTHING THE WAY



*Helping Children
Cope with Inflammatory
Bowel Disease*

WHAT NOW?

At last – a diagnosis. Your physician has told you that your child has either Crohn’s disease (CD) or ulcerative colitis (UC), or perhaps an indeterminate colitis. In any event, you now know that your child has a chronic illness classed as inflammatory bowel disease (IBD). This means that your child will not outgrow IBD although there will be times when his disease is active (known as a flare-up or an acute attack) and times when his disease is quiet (known as a remission).

With the diagnosis, you may feel some relief (at last, someone knows why my child has been ill for so long), some shock (what happens now and how do we cope?) and perhaps even a sense of being overwhelmed by the news. All of this is understandable and perfectly normal. But what do you do now?

You can start by learning more about IBD. Information about IBD will help you and your child cope with the disease and give you back some sense of control over the situation. This booklet, along with other booklets provided by the Crohn’s and Colitis Foundation of Canada (CCFC) will assist you and your family in understanding IBD. It will also educate your child’s teachers and the school system so they can support and encourage your child through the challenges of IBD.

For more information, please pick up our other CCFC booklets; go to our websites www.ccfc.ca and www.thegutsgeneration.ca, join your local CCFC chapter, subscribe to our publication “**the Journal**” and read as much as you can about IBD.

Remember – knowledge is power!

IBD IS NOT IBS

Let's start off by clarifying that inflammatory bowel disease (IBD) is NOT irritable bowel syndrome (IBS). Many people confuse these two diseases because they sound so much alike and both have symptoms that seem comparable. In reality, IBD and IBS are very different diseases.

With IBD, symptoms develop because of inflammation in the gut. IBS, on the other hand, is thought to arise because of changes to bowel function or the way the brain senses what is going on in the bowel – inflammation does not play a role. Unfortunately, and to add confusion to the situation, it is possible to have IBD and the additional symptoms of IBS.

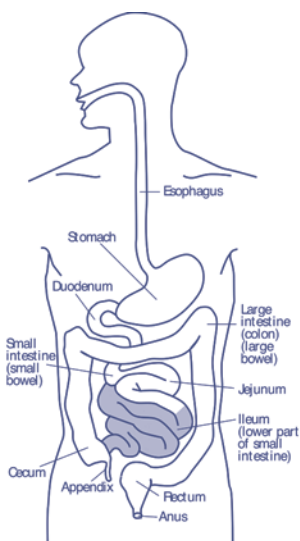
If IBD is not IBS – what is inflammatory bowel disease? Let's begin by taking a closer look at the digestive tract.



THE DIGESTIVE TRACT AND INFLAMMATORY BOWEL DISEASE

The digestive tract or gastrointestinal (GI) tract is essentially a tube that starts at your child's mouth and ends at her anus. When she eats and drinks, food travels from her mouth to her esophagus, then onward to the stomach, small intestine (or small bowel), large intestine (also known as the large bowel or colon), her rectum and finally her anus. The whole system is finely balanced to promote optimum nutrition and health.

The stomach is your body's "holding tank," initially breaking down food and passing it along to the intestines. Nutrients from food are actually absorbed into the body from the small intestine. From there, water and minerals are absorbed in the large bowel and finally the remnants of the digestive process, known as feces, are passed to the rectum and then expelled from the body via the anus.



CROHN'S DISEASE AND ULCERATIVE COLITIS

IBD really describes a condition that can be either one of two disorders – Crohn's disease (CD) or ulcerative colitis (UC). People have one disease or the other but not both. When the diagnosis is not yet clear, colitis may be called "indeterminate colitis."

Crohn's Disease

With Crohn's disease (so named after the doctor who first described it in 1932), inflammation can occur anywhere in the GI tract but is usually present in the lower part of the small bowel and the colon. Patches of inflammation occur between healthy portions of the gut and can penetrate the intestinal layers from inner to outer lining. Medication and surgery alleviate the symptoms of CD but do not cure it.

Ulcerative Colitis

Ulcerative colitis only affects portions of the large intestine, including the rectum and anus and typically only inflames the innermost lining of bowel tissue. It almost always starts at the rectum, extending upwards in a continuous manner through the colon. UC can be controlled with medication and in severe cases, can even be cured by surgically removing the entire large intestine.

Both CD and UC can flare up at unpredictable times. In fact, doctors and researchers are not sure what causes a person to go into remission and what launches an acute episode. We do know that contrary to what you might think, diet and stress do not precipitate a recurrence of your child's disease, although they may aggravate her symptoms.

SYMPTOMS AND CHALLENGES OF IBD

Unlike many other diseases, IBD is “invisible.” In fact, due to the side effects of certain medications, your child may even appear to be robust and healthy. In some ways, this makes it more difficult for him because his health challenges are not as obvious as someone who might be in a cast or sling.

Because IBD inflames the lining of the GI tract, it disrupts your child’s ability to digest food, absorb nutrients and eliminate waste in a healthy manner. As a result, he may suffer with any or all of the following symptoms:

- abdominal pain
- cramping
- gas and bloating



- fatigue
- diarrhea (possibly bloody), often frequent and urgent
- loss of appetite

Adults and children with IBD often have an urgent need to go to the bathroom. The diarrhea caused by the disease and the “false urges” that sometimes accompany a flare-up of the disease necessitate frequent trips to the bathroom throughout the day. As you can imagine, this can be very embarrassing for your child. We will talk about strategies to cope with this later in the booklet.

During a flare-up, children and teens may want to avoid food because of the subsequent cramps, vomiting and diarrhea. Not surprisingly, this can lead to inadequate nutrition and add to his feelings of fatigue and lethargy. This can also cause difficulties with school work, concentration, chores and athletic activities. As a parent or teacher, you need to be aware that a child with IBD may simply not have enough energy (during a flare-up) to participate as fully in life as he usually does. Give him time and your support during an acute episode of his IBD while encouraging him to do as much as he can.

Lack of nutrients can also lead to weight loss, as well as a delay in growth and physical maturation. It is not uncommon for children with CD to appear smaller and younger than their friends. However, take heart! Your child will have a growth spurt and he will eventually go through puberty, albeit later than his peers.

A HEALTHY APPROACH TO MANAGING IBD

We are fortunate to live in a world where a vast array of medical, nutritional, pharmaceutical and surgical options can alleviate much of the distress caused by CD or UC. We will touch briefly on each of these areas, however for more detail, please go to our booklets: *"Prescription for Health: Medication and IBD," "The Cutting Edge: Surgery and IBD"* and *"Food for Thought: Diet, Nutrition and IBD."* In addition, the CCFC booklet, *"Surviving and Thriving with CD and UC: A Guide to IBD"* provides you with a general overview of the challenges and approaches to living with IBD.

1. Medication

Be aware that all medications, prescription or otherwise, have side effects. As a result, your child's healthcare team (which includes you!) must find a balance that maximizes his well-being while minimizing any negative side-effects.

In general, medications fall into one of two very broad categories:

- ▶ drugs that are used to reduce inflammation (and may therefore reduce some of his symptoms); and
- ▶ drugs that are aimed only at symptom-reduction and do not affect the inflammation in his gut.



a) Drugs for Reducing Inflammation:

Examples of the types of drugs available to combat inflammation include:

CLASS	DESCRIPTION
Sulfasalazine and 5-Aminosalicylates (5-ASA)	Limit the production of certain chemicals that trigger inflammation
Steroids	Reduce inflammation
Immunomodulators	Alter how the body mounts an inflammatory response
Biologicals	Target and block molecules involved in inflammation
Antibiotics	Do not counteract inflammation directly but decrease infection that can cause, or result from, severe inflammation

Some drugs, known as immunosuppressants, suppress the body's immune response. Recent research seems to indicate that there may be a slightly increased risk of infection when given to children. In addition, there is a very small risk (in the range of 1 in 5,000 to 10,000 patients) of developing cancer of the lymph glands (lymphoma). Immunosuppressants pose the classic dilemma of risk versus benefit, where a small risk with big impact has to be weighed against an immediate and tangible benefit. Talk with your child's specialist about the pros and cons of all the medications being prescribed.

b) Drugs for Managing Symptoms:

Note that many of these drugs are available “off the shelf” in your pharmacy. You should NOT self-prescribe; talk with your doctor first.

- ▶ Antidiarrheals: do not give these to your child during a flare-up as they may cause other complications! Check with his doctor.
- ▶ Antispasmodics: relax muscles in the wall of the GI tract to reduce cramping
- ▶ Bulk formers for stool: soak up water in the stool, thereby firming it up and lessening looseness as well as frequency
- ▶ Bile salt binders: prevent irritation of the gut by capturing bile salts
- ▶ Stool softeners: for softening feces to ease bowel movements if your child has hemorrhoids or anal fissures. Again, talk with your child’s doctor before trying these.
- ▶ Analgesics: for pain reduction
- ▶ Non-steroidal anti-inflammatory drugs: for pain control in joints (but note that some people find these drugs aggravate their abdominal pain and diarrhea)
- ▶ Acid-reducing drugs: for “heartburn”
- ▶ Vitamins and minerals: may be needed as supplements

2. Diet and Nutrition

Everyone needs to have a well-balanced diet for good health, vigour and healing, but you need to pay special attention to your child’s diet if she has IBD. As we mentioned before, your child may have a tendency to avoid eating during flare-ups because of subsequent abdominal pain, diarrhea and nausea. Malnutrition may result not only because she is not eating, but also because of the difficulties her gut has in absorbing nutrients. This may lead to weight loss and fatigue, as well as delays in growth and puberty.



Your child's doctor may advise you to use supplements including vitamins and minerals such as calcium, Vitamins D, B12, C, folic acid, iron, zinc and magnesium. Speak with your physician and dietitian for more information on what would be appropriate for your child, as well as the best way to administer them for maximum benefit.

It is interesting to note that current research indicates that what your child eats does not cause a flare-up, but it may **exacerbate (increase)** her symptoms if she eats "trigger" foods. Trigger foods are those which aggravate her gut and are individual to her. Identifying those foods which are triggers for your child is an important part of your day-to-day strategy in helping her live well with IBD.

Conversely, you should also identify what are her "safe" foods. These are foods which are unique to her and do not appear to bother her digestive tract. Examples of foods that appear to be "safe" for many people include white rice, white bread, bananas, applesauce and toast.

Liquid Supplements

You may find that your child will accept a liquid nutritional supplement when regular food is unappealing to her. These supplements generally offer balanced nutrition, are easily digested and give your child's gut a chance to rest. Consult your physician, dietitian or pharmacist for suggestions on how and what would be appropriate.

Enteral Feeding

Enteral feeding (ET) is another strategy used by some physicians as a primary therapy to treat CD or as a secondary treatment for malnutrition and growth failure. With ET, a nasogastric (NG) tube is inserted down your child's nose into her stomach and a medicinal food supplement is then administered through the tube. If your child receives ET while she sleeps at night, she can remove the NG tube in the morning or disconnect it and tuck it behind her ear during the day. This therapy may sound strange at first, but be assured that children adapt to it very quickly and it has been used successfully for many years.

ET treatments may last from one to three months if all of your child's nutritional needs are being met this way, or for many months if she is receiving a nightly supplement for malnutrition. In that case, many children choose to have a stomach tube (gastrostomy) for nocturnal feedings, instead of an NG tube.

On occasion, if a child is acutely ill and unable to get adequate nutrition either by mouth or enteral feeds, it may be necessary to place her on total parenteral nutrition (TPN). In this case, liquid nutrition is administered through an intravenous site (rather than through an NG tube). TPN is usually administered in the hospital, but in some cases may be provided at home if a teaching program and follow-up support are available in the community.

3. Surgery

Approximately 70% of people with CD and 40% of those with UC will require surgery at some point in their lives. When children develop IBD the disease tends to be more aggressive, so an aggressive surgical approach may similarly be required to circumvent difficulties that could lead to growth problems.

Surgery for Ulcerative Colitis

Removal of the large intestine and rectum (colectomy) effectively removes ulcerative colitis from your child's gut, with the result that he is "cured" of UC. Because the rectum is gone and thus the passage for feces has been removed, his surgeon may have also created an ileostomy (connection of the small bowel to the exterior of his body). An ileostomy uses a bag (otherwise known as an ostomy appliance) attached to the skin of his abdomen for the elimination of feces.

In some cases, surgeons can convert an ileostomy to an ileal pouch anal anastomosis (IPAA). For those people who are eligible for this surgery, the IPAA offers a high degree of satisfaction because a pouch for collecting feces is made inside the body and stool continues to be expelled through the anus rather than into an ostomy bag.



Surgery for Crohn's Disease

Because CD can involve any part of the GI tract, surgical treatments can be many and varied. If your child has acquired an abscess, stricture or obstruction, a resection (removal of all or part of a section of the gut) may be required to repair the problem. In some cases, a strictureplasty can be done to open up a narrowed segment of the intestine. As with UC, a colectomy and ileostomy are possible surgeries.

The IPAA is not usually performed on patients with CD because unlike UC, the disease can recur after the procedure is done. Should this happen, it would necessitate further surgery and potentially the removal of the internal pouch.

In addition to bowel-specific surgery, patients with CD can also have surgery to treat problems associated with complications of the disease. For example, if your child has developed a fistula, there are procedures available to reduce the pain and pus.

Laparoscopic Surgery

Minimally invasive surgery, or laparoscopic surgery, is performed through small incisions in the abdomen with the aid of special instruments and a camera. Because of the smaller scars, younger people find the prospects of this surgery more appealing than "open surgery." In addition, healing time is faster and there is less post-operative pain.

Unfortunately, not all IBD patients are candidates for laparoscopic surgery, usually because of extensive scarring (adhesions) within the abdomen or because the disease is so extensive that a wider field of view is needed than that offered by the scope.

HELPING YOUR CHILD COPE WITH IBD

Children can be very resilient. However, they take their cues from you, so your attitude about IBD and life is critical to their outlook. Children with IBD can live full and rich lives, with a future filled with career, marriage, children, sports and other activities. Yes, there will be times when CD or UC flares up and some things may need to be put on the back burner for a while, however with proper management, there are many opportunities for your child to be just like other kids.

This is an important issue for children. They do not want to be seen as different from other children; being regarded as such can be an issue for their self-esteem, their body image and their confidence.

Sports and Hobbies

We encourage you to get your child involved in hobbies and sports. When his IBD flares up, encourage him to participate in activities that are less active in nature, but nonetheless keep him engaged and occupied. This is important for his physical health as well as his emotional well-being.





Emotional Ups and Downs

Chronic disease may cause an emotional roller coaster for you and your child, particularly if she is older and the diagnosis comes right at the time when her self-esteem and body image are fragile. On occasion, she may even become depressed. Keep in mind that this is not abnormal and in fact, research indicates that it happens in approximately 50% of all cases where children are diagnosed with IBD.

Be alert to any signs that your child is withdrawing or having difficulties coping with school, friends and activities. If this happens, seek support from your healthcare team to reassure her and help her cope. A counselor or child psychologist can be of enormous help; don't be afraid to ask for assistance for your child, or for you. It is also important to know that most children will become much happier and more optimistic once their disease goes into remission.

Emotional Impact on the Family

It is important for you, as parents of a child with IBD, to know that the impact of having a youngster with CD or UC can have a significant effect on the entire family. There is no getting around it – when

someone in your family is ill, the whole family can experience emotional strain as everyone seeks ways to cope. This is normal; don't be too hard on yourself or on other members of the family as you work through the challenges together. Seek the support of your healthcare team, friends, and your child's teachers – don't try to do this alone.

Don't forget the Crohn's and Colitis Foundation of Canada has local chapters across the country. By joining one near you, you will meet other parents who are learning how to support a child with IBD, and you will have access to information that will enable you to help your son or daughter.

The Need for Independence

It is natural for a parent to feel very protective of a child with IBD; however, be careful not to overdo it. In fact, it is wise to encourage your child to assume responsibility for his medical routines as soon as he is mature enough to handle it.

Sometimes, medication routines can become a source of conflict between parent and child, particularly if he has reached the age where he is looking to be more independent. In fact, some adolescents rebel against their disease and their treatment, unconsciously using denial as a way of dealing with their illness.

Just like any other issue, it is important for you to keep talking with your child. Encourage him to talk and again, seek the support of your healthcare team in getting your child to air his emotions and come to grips with his fears.

And remember – IBD does not define your child. IBD may be a part of his life, but he is so much more than his diagnosis.

Friends

Friends are a very important part of a child's life. Your child may wonder what to tell her friends about her disease, or if she should say anything at

all. After all, IBD is difficult to explain and the fear that some of the other children may be thoughtless and cruel after such a discussion may only make your child feel more vulnerable. This is an area where you, as a parent, should respect her decision and support her in her choices. If she wants to share her diagnosis with friends, then by all means assist her in explaining what IBD is all about. If she prefers to keep her condition private from her friends, respect that choice whenever possible.

Teachers and School Administration

Even if your child prefers not to tell his friends, it is preferable that his teachers, school administrators and school nurse be advised of his condition. Contact the school and let them know that your child has IBD, and share information about the disease. Give them a copy of this booklet. Help the staff and your child by letting them know what to expect and what they can do to ease the school day situation

Suggestions for the School Day

Talk with your child's teacher about the need for her to make frequent bathroom trips throughout the school day. Work out strategies such as placing your child at a desk close to the classroom door and allowing her to leave without





requesting permission, to facilitate hassle-free exits that do not draw attention to her.

You may need to make arrangements with the school nurse for medication administration throughout the day. Try to set it up so that your child can discreetly leave class, again without the need to request permission thereby creating a potentially embarrassing situation for her.

The school nurse can also be very helpful in arranging for the use of a bathroom other than the student washrooms. Having frequent diarrhea is bad enough, but using the toilet in a public area with lots of other children around can be excruciatingly embarrassing.

Incidentally, it would be a good idea for your child to have a spare set of underwear and pants tucked away at school in case she suffers from an accident. Her school nurse may be able to help out by storing them for your child and giving her a place to change if she needs it.

Keep the school informed about your child's health, including when she is suffering from any flare-ups. Hospitalization and absence from school are real possibilities, so make arrangements for at-home curriculum materials, tutoring and make-up tests when they are needed. Also let the school know that even though your child is back to school after a flare-up, she may still be feeling fatigued and listless for a while.

REACH OUT

To find out more about IBD, please go to the Crohn's and Colitis Foundation of Canada website www.cffc.ca. There you will find more information, additional booklets on a variety of topics such as diet, medication and surgery and the phone numbers and addresses for a CCFC chapter near you. Reach out and talk with other parents who are learning how to support their children; make some new friends and enrich your own life as well as that of your child.

Remember, IBD does not have to limit your child's life. Together with your healthcare team, your own confidence and knowledge about IBD and the support from other members of your family, friends and teachers, you can provide an environment that will inspire your child to live life to the fullest.

Good luck in your journey and remember – you are not alone. By funding IBD research, the Crohn's and Colitis Foundation of Canada is working every day to find the cures, causes and treatments for Crohn's disease and ulcerative colitis. Please join us in our journey and together, we will find the cure for inflammatory bowel disease.

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For more information on Foundation activities, visit our website (www.cffc.ca) and join our team today!

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