



Crohn's and Colitis
Foundation of Canada

Fondation canadienne des
maladies inflammatoires
de l'intestin

Kids and

INFLAMMATORY

BOWEL

DISEASE



What is IBD?

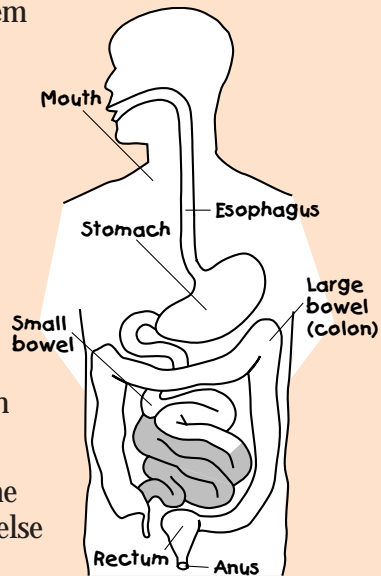
Inflammatory bowel disease is known as “IBD” for short.

IBD is a general name used to describe Crohn’s disease and ulcerative colitis.

They are both diseases of the digestive system.

Here is what your digestive system looks like:

1. Mouth
2. Esophagus (swallowing tube)
3. Stomach
4. Small bowel
5. Large bowel (colon)
6. Rectum
7. Anus



Ulcerative colitis happens only in the large bowel.

Crohn’s disease can happen in the large bowel, and also anywhere else in the digestive system.

With IBD, part of the digestive system becomes inflamed. That means it is swollen and sore. It can become very raw, and sometimes it may bleed.

Some of the things that can happen are stomach pain and cramps, gas, throwing up, a bloated stomach, fever and diarrhea. These things can make people feel very tired. All of these things are called symptoms.

People with IBD may have to go to the bathroom many times during the day and night. This can make their bums quite sore. Their bums can also hurt because they wipe them so often.

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

Sometimes, people with IBD might not feel like eating.

That could make them lose weight and feel tired. It is especially important that kids with IBD keep on eating so that they'll keep growing.

Thousands and thousands of Canadians have IBD. Some people with IBD have really bad symptoms and need a lot of medical care. Other people with IBD don't have as many problems.

IBD comes and goes quite suddenly. Some people will feel ill because of their IBD only once. Other people might feel ill more often. A lot of the time, though, they will feel perfectly well.

What causes IBD?

No one knows what causes IBD. We only know that some people happen to get it. No one does anything to make themselves sick with IBD.

IBD is not contagious. You can't catch it or pass it on to anyone else, the way you can a cold.

Sometimes, two or more people in the same family have IBD. We don't know why this happens.

IBD is a "chronic" disease. That means people who have IBD, have it all their lives. They don't usually die from IBD. Sometimes, it will make them feel badly. Other times, they will feel great. Over time people learn what to do, and what not to do, to feel better.

Most of the time though, they can do the same things that everyone else does. They go to school and they get jobs. They get married and have kids. They try to lead a regular life, just like everyone else.

Medical Help for IBD

Even though medical experts don't know what causes IBD, they can help people with IBD feel better.

They can give advice on how to eat properly.

They can give medicine.

They can do surgery.



Eating Properly

Good nutrition is important, especially for kids. The right nutrition comes from a healthy diet and helps kids grow up and develop properly. This is why parents are always nagging kids to “eat, eat, eat” all the time.

Sometimes, people with IBD find that certain foods may make them feel worse. They don't want to eat those foods, even though they are important to their diet.

Sometimes, they won't want to eat anything at all.

The food they do manage to eat may not stay in the body long enough to supply it with the “fuel” it needs to work. When someone doesn't get enough fuel, this is called malnutrition.

A dietitian is a medical expert on eating. He or she can provide advice on how to eat properly.

Most of the time, people with IBD eat the same foods as anyone else. The doctor, dietitian, or nurse might suggest cutting out certain foods, or taking “supplementary,” or extra, nutrition. Supplementary nutrition is one way to be sure people with IBD get all the vitamins and minerals they need to grow. The nutrition is in liquid form, so the bowel doesn't have to work hard to digest it. This gives the bowel a chance to rest.

Some people drink their supplements, like a milkshake. In other cases, liquid food is pumped through a tube directly into the stomach. This tube is either inserted through the nose or through a special hole that doctors have made on the stomach. These feedings are usually done at night, while the person sleeps. They may have to be done in a hospital or may be done at home. Some people become experts at feeding themselves this way.

It doesn't happen very often, but sometimes people with IBD cannot eat anything at all. When this happens, they may be given "TPN," which is short for total parenteral nutrition. This means that liquid food is put directly into their veins. With special training this intravenous feeding may be done at home. The person doesn't feel hungry and doesn't have to eat, but is getting the nutrients he or she needs.



Medicine

A doctor who is an expert in IBD is called a gastroenterologist. Many family doctors also treat IBD.

There are many medicines for IBD and each has its own effect. The doctor may prescribe different medicines that do different things.

Some medicines stop the bowel from swelling up. These are called "anti-inflammatory" medicines.

Other medicines make a person with IBD feel better. For example, some medicines will stop diarrhea or cramps.

Medicine can fix other problems that may develop from IBD. For example, someone with IBD might get sores on his or her bottom. Antibiotics may heal these sores.

Unfortunately, some medicines have side effects.

Some medicines can make a person feel queasy. They may change the way the person looks. For example, some people with IBD take steroids. This medicine makes their faces look really round, and causes pimples. But when the medicine is stopped, these things stop too.



Surgery

People with IBD may have surgery, or operations, to make them feel better. The need for surgery is always discussed with a doctor ahead of time.

Some operations are really simple and can be done right in the doctor's office or clinic. For example, people with IBD can have a sore bum because they get pimples or tiny cuts that are filled with infected fluid. An operation can drain the fluid and close the opening.

Some operations for IBD have to be done in a hospital. For example, Crohn's disease can make the bowel get thicker and thicker. One day, food could get blocked up inside the bowel. This is called an obstruction. A surgeon can unblock the bowel and make it wider. This makes everything work properly again.

Sometimes, the best way to handle Crohn's disease is to have a surgeon take out the section of bowel that has the disease, and then sew together the remaining healthy bowel. This is called a resection.

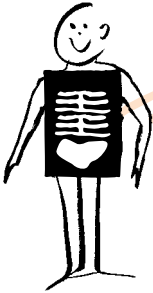
The disease might come back, but in the meantime, the person feels a lot better.

Sometimes, the best thing to do for ulcerative colitis is to have the entire colon taken out. This gets rid of the disease. It will never come back. This operation changes the way the person goes to the toilet. They still pee the usual way, but it means they

People with IBD may have surgery to make them feel better.

have bowel movements differently. The surgeon may create a pouch inside the body for the waste to be stored in. Or, the remaining bowel is connected to the outside of the abdomen and a special plastic bag is then attached to collect the bowel movements.

Both the pouch and the bag need be emptied several times a day.



Testing, Testing 1-2-3

To figure out for certain if people have IBD, they will probably go to a hospital or clinic and have medical tests done.

After they know for sure, they may still have to have tests, but not as often.

Once in a while, the doctor will take blood samples and the blood will be studied. This might be done to be sure a medication is working properly.

Blood tests also show if the body is getting and using all the right “fuel” from food. This is important, especially for kids, because they need nutrients to be healthy and keep growing.

Sometimes a person with IBD will have an x-ray after drinking a liquid that looks like a milkshake. (It doesn't taste like one, though.) An x-ray is a photograph that shows what the insides of the body look like. The milkshake coats the digestive system with a liquid called barium. The barium makes the x-ray clear and sharp. Barium passes out of the body when the person goes to the toilet later.

Another type of x-ray that combines computer images is called a CAT scan.

Sometimes the doctor will use an ultrasound machine, instead, to make a picture of the digestive system. The person doesn't have to swallow anything. The doctor rubs a cool jelly on the stomach and then rolls an instrument across it. The instrument is no bigger than a flashlight. It makes a picture of the digestive system, which can be seen on a television monitor.

Sometimes, instead of an x-ray, the doctor will use a "scope" to examine the digestive system. The scope is a very tiny camera that fits on the end of a very thin tube that bends easily. The tube is passed down the throat or up the bum and taken out after the examination.

Some people are uncomfortable during this test, so they might need to take medicine that puts them to sleep during the test.

IBD can be difficult, even for adults, to understand. Even if hospitals, clinics and doctors' offices are very busy places, it's okay to ask medical people to explain things. Everyone deserves to understand what's happening and why.



Life with IBD

People with IBD want to be just the same as everyone else. This is especially true of kids.

When their IBD isn't bothering them, people go to school or work, play sports, have hobbies, and do all the things everyone else does.

When IBD is bothering them, things may be different. They may miss school or work. They may be too sick or too tired to play or do things for long periods of time. They may have to go to the toilet a lot. Sometimes they may need to go to hospital to get rest or to have an operation.

People with IBD can feel that IBD is really messing up their life and they are missing out on a lot. Other times, people with IBD will have a normal life.

Kids with IBD might worry that they're not growing as fast as their friends.

It is true that some kids with IBD may not grow as quickly, but they will catch up. IBD doesn't **stop** growth, it only **slows down** growth for a little while. A kid with IBD may seem younger and smaller than his or her friends, but watch out! As long as they follow treatments and get enough nourishment to grow, one day they will be the height they were meant to be.



Feelings Matter

People that have IBD may have all kinds of confusing feelings about the disease and themselves. They may feel sad, mad, guilty or embarrassed. They may wonder “Why me?”

It's okay to feel badly about IBD.

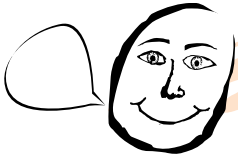
People with IBD can help themselves by talking about how they feel. They can talk to their families, doctor and other medical experts, their friends, the people who are important to them.

It is important to be able to talk to others and have them listen. Most people are very understanding about IBD. The doctor or nurse can help you explain IBD further.

Some people don't mind talking about their IBD. Other people would rather not talk too much about it. That's alright too.

If you, or someone you know, has IBD, ask questions so you understand what's happening. People have different symptoms and different treatments. Not everyone has surgery or has to stay in hospital.

Learn about IBD so you can answer other people's questions too.



Talking About IBD

People who have IBD are people just like you. They share their lives with family and friends and many other people.

It can be hard, or embarrassing, to explain IBD to other people. Most people don't really know anything about IBD. Or, they may have wrong or silly ideas about IBD.

Now that you understand IBD, you can explain it to them.

You can give them the facts.

It's okay to talk about IBD. It's part of life.

A person with IBD will sometimes feel great, and sometimes feel bad. They will learn what to do, and what not to do, to feel better.

Some day, there will be a cure for IBD. Meanwhile, we are learning more every day about how to live with IBD.

Together, We Can Find the Cure

The Crohn's and Colitis Foundation of Canada (CCFC) was started in 1974 by the parents of children who have IBD. These parents hope that one day we'll find a cure for IBD, through medical research.

The Foundation raises money to pay for this medical research. Since 1974, the CCFC has raised millions of dollars and paid for more than a hundred research projects. With the Foundation's help, Canada has become a leader in medical studies of IBD.

The Foundation publishes brochures like this one, that explain IBD to people who have these diseases, and to their families, health professionals and the public.

Help Us Finish the Job!

Perhaps you and your family would like to help the Foundation find the cure for IBD.

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: _____

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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
- 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, 600 - 60 St. Clair Avenue East, Toronto, Ontario M4T 1N5. For more information on activities in your area, contact your Regional Office listed on the next page.

Crohn's and Colitis Foundation of Canada

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