

Are you new to the IBD Crew? Advice for the Newly Diagnosed



Are you new to the IBD crew? It is nothing if not **OVERWHELMING!** Youth are already dealing with a complex and confusing time in life, and now this? Although, it may be a pain in the butt there are many who have found it a hidden blessing in appreciating the good days and not taking your health for granted! Some people have even been inspired to change themselves or the world around them by things like **researching, volunteering, fundraising, networking**, and forming **new friendships** based on their new found commonality with other youth or individuals effected with Crohn's disease or Ulcerative Colitis.

Okay, first things first: What on earth is **IBD**? The official definition of IBD is **Inflammatory Bowel Disease**. (*some like to say **Icky Belly Disease***). IBD can be grouped into two categories: Crohn's disease (CD) and Ulcerative Colitis (UC). Both Crohn's and UC have similar symptoms, reactions and medications but they differ in what part of the intestinal system the disease affects (or where it lives!). In Crohn's disease everything from gum to bum is affected and the affected area may move along the digestive tract (all 9 metres of it!). Whereas, with Ulcerative Colitis the only area affected is the large intestine - **the colon**. The affected areas may become inflamed, develop sores (fistulas) and bleed. Symptoms vary and in addition to diarrhea, fever and pain may include non-gastrointestinal symptoms such as arthritis, weight loss and fatigue.

IBD is a chronic condition (yes, that means we are in it for life!) that currently has no cure. There are periods of **remission** where you will be almost completely or completely without symptoms and then periods of **flare-ups**+aka active disease periods (when you feel sick and have the symptoms of the disease). IBD affects everyone differently and some people stay in remission for years while others are not so lucky and stay in remission for only a short while (i.e. couple days or weeks). Flare ups can be random or can stay consistent until the right medication is found or surgery is performed.

Symptoms of IBD

- Fatigue
- Diarrhea
- Vomiting
- Belly pain & cramps
(Abdominal pain)
- Nausea
- Fever
- Blood loss/mucus (in
the stool)
- Weight loss/gain
- Sore joints
- Unpredictability of
bathroom breaks and
waking in the night
- Skin lesions (red
bumps on the legs
called erythema
nodosum/pyoderma
gangerosum)
- Arthritis/joint pain
- Sores in the mouth
- Eye infections
(episcleritis/uveitis)

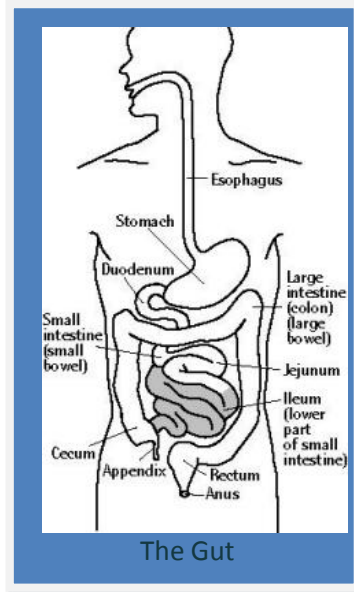
Getting Diagnosed- The A, B, C's!

If you think your symptoms sound like IBD, talk to your family doctor. They are most familiar with you and your family history and will be able to give you some direction. They will most likely send you for some initial tests or immediately refer you to a **GI (Gastroenterologist)** specialist.

The Gastroenterologist has all of the fun tools to help diagnose you. There are a couple different ways it can be determined if you have IBD. (See the Tipsheet Glossary for more information on these tests).

Colonoscopy and Biopsy
Barium Enema
Blood tests
Upper GI

After you have been through a slew of tests and had white liquid poured down your throat and tests performed on your key parts, you'll have to wait. Your GI or the Radiologist (X-ray reader) will inform your doctor of the results and further verification may be needed if they suspect IBD.



Next Steps....Living with IBD

Now you really are part of the IBD Crew, so it is important to learn from those who have gone before and find out a few tips on how to live well with IBD.

It's ok to be sick! Don't add to the list of your symptoms by worrying about missing out on life. It will be there when you are better. Don't rush or push yourself too much when under the weather. You may push too hard to get one step ahead and find you've gone two steps back instead. Don't let the illness get too severe. Get in touch with the proper medical professional as soon as possible if the need arises!

- * One great thing for newly diagnosed people is a **medic alert bracelet**.
- * Talk to other youth or people with IBD: believe me, it helps!
- * Start a collection of tips and tricks from doctors, other IBD patients, dieticians, and other experts.
- * Don't worry about being sick. Everyone gets sick.
- * Catch up on old favorite television shows. Stock up on Seasons 1-6 of Sex and the City!
- * Attitude makes a big difference. Try to stay positive.
- * Keep a diary of symptoms (what and when) and a medication diary of what you have been on and when.
- * Be responsible for your own health. Keep track of dates of tests, where they were done and become an expert on YOU!

- * Most IBD patients see many doctors and have many appointments. Don't feel like you are the only one. We understand the frustration.
- * Bring someone with you to your appointments whenever possible. Research shows we lose most information the doctor tells us once we leave, so if you have someone else there they can help you remember.
- * Follow the directions on medications! (If it says drink lots of water, make sure you do to avoid further medical issues).
- * Keep a list of questions and symptoms to bring with you to the doctor. When many people get to their doctor's office they forget how long or when specific conditions started, or questions they wanted to ask. Bring this list to ensure all your questions get answered.
- * **You are not alone!!** We understand.

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