

Welcome to Week 2 of the Crohn's & Colitis Foundation of America (CCFA) Online Support Group.

Last week's material consisted of an overview of inflammatory bowel diseases (IBD), specifically Crohn's disease and ulcerative colitis. This week's material will focus on the medical management of these conditions, including medical therapies, surgical interventions, and complementary and alternative options.

So let's begin by looking at the overall goals of treatment for Crohn's disease and ulcerative colitis.

There are three main goals:

- **Achieving remission** (defined as the absence of symptoms)
- **Maintaining remission** (defined as preventing flare-ups of the disease)
- **Improving quality of life** (defined as each individual perceives it)

These goals may be attained through the use of a comprehensive IBD management plan which would:

- Control symptoms
- Minimize treatment side effects
- Ensure appropriate nutrition intake
- Treat complications
- Prevent cancer
- Address any emotional and social issues

For most patients, IBD can be managed so that the impact on their quality of life is as small as possible. Yet even for those in long-term remission, these diseases can flare without warning. Thus, understanding IBD and how it can affect you is central to controlling the disease and to developing an approach that is positive and adaptable to changing situations.



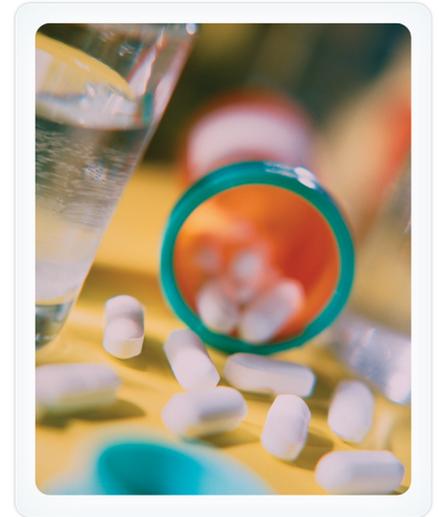
? Are your symptoms managed? Do you feel your quality of life has improved since treatment started?

What you should know about prescription medications

While there are many effective treatments to help control IBD, there is no single ideal therapy. Your healthcare team will work with you to customize a treatment plan to your needs, but it's important for you to have full understanding of available options. Keep in mind that taking medication can significantly reduce the risk of flares and of developing complications related to IBD, so even though a medication may have a chance of causing side effects, potential benefits may outweigh risks.

Doctors use a variety of medicine for IBD diseases. The five main categories are:

- 1 Aminosalicylates:** These medications, such as sulfasalazine, balsalazide, mesalamine, and olsalazine, help control inflammation by delivering a compound containing 5-aminosalicylic acid (5-ASA) to the bowel and can be given either orally or rectally. They are effective in treating mild-to-moderate episodes of IBD. They also are useful in preventing *relapses* (return of symptoms).
- 2 Corticosteroids:** These medications, which include prednisone, prednisolone, and budesonide, affect the body's ability to begin and maintain an inflammatory process. They can be administered orally, rectally, or intravenously. Effective for short-term control of acute episodes (called *flares*), they are not recommended for long-term (greater than a few months) or maintenance use due to their side effects.
- 3 Immunomodulators:** These medications, which include azathioprine, 6-mercaptopurine (6-MP), methotrexate, and cyclosporine, modify the body's immune system so that it cannot cause ongoing inflammation. Given orally or by injection, immunomodulators are typically used in people when aminosalicylates and corticosteroids haven't been effective, or have been only partially effective. They also may be effective in maintaining remission in people who haven't responded to other medications.
- 4 Biologic therapies:** These therapies are genetically engineered to target very specific molecules involved in the inflammatory process. They include adalimumab, certolizumab pegol, infliximab, and natalizumab. These medications are useful for people with moderately to severely active disease. They also are effective for reducing *fistulas*. (You may recall that fistulas are small tunnels connecting one loop intestine to another or two organs in the body that are usually not connected.)
- 5 Antibiotics:** Metronidazole, ciprofloxacin, and other antibiotics may be used when infections—such as an abscess—occur. They treat Crohn's disease, colitis and perianal Crohn's disease. They are used for post-surgical problems such as pouchitis (a condition that can follow surgery to remove the colon).



It is important to keep in mind that a person's therapeutic needs may change over time. What works at one point during the illness may not be effective during another stage. It is important for the patient and doctor to discuss thoroughly which course of therapy is best—bearing in mind that a combination of therapies may be the optimal treatment plan.

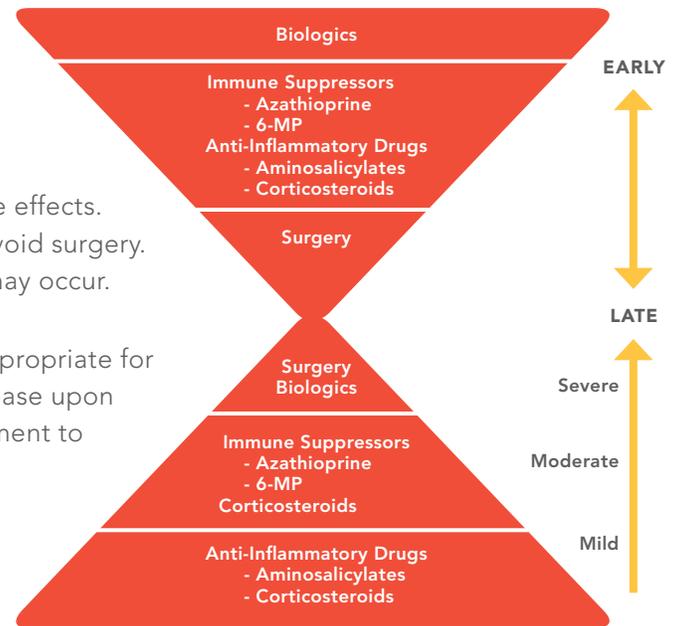


Have you discussed all treatment options, including benefits and risks, with your healthcare team?

What are "Top-Down" and "Bottom-Up" strategies?

There are two strategies doctors use in treatment programs:

- 1 **Top-Down** minimizes steroid use and their associated side effects. It also promotes early mucosal healing and may help to avoid surgery. However, toxicity is a possible side effect and infections may occur.
 - 2 **Bottom-Up** is a more traditional approach and may be appropriate for many patients. But, patients with moderate-to-severe disease upon diagnosis may benefit from earlier, more aggressive treatment to induce and maintain remission.
- ? Do you know what strategy your doctor has chosen for you?



Other medications can help with symptoms.

While prescription medications reduce intestinal inflammation and form the core of IBD treatment, they may not eliminate all of your symptoms. Naturally, you may want to take over-the-counter medications in an effort to feel better. But before you do, consult with your doctor.

When over-the-counter medications are appropriate for symptom control, your doctor may recommend loperamide to relieve diarrhea or anti-gas products for bloating. To reduce joint pain and fever, your doctor may recommend acetaminophen or nonsteroidal anti-inflammatory drugs (NSAID)—such as aspirin, ibuprofen, or naproxen. NSAIDs will work to alleviate symptoms, but can irritate the small intestine or colon and promote inflammation, so they need to be used carefully.

Let's review surgical options for individuals with IBD.

The decision to have surgery to help manage a patient's IBD disease should be, when possible, a well-thought-out process in order for the patient and family to understand all surgical options.

There are several different types of surgical procedures that may be performed, depending on the type of

complication, the severity of the illness, or the location of the disease in the intestines. Here are details on the most common surgeries.

CROHN'S DISEASE	ULCERATIVE COLITIS	PRIMARY GOALS OF SURGERY
<ul style="list-style-type: none"> - Strictureplasty - Resection of small intestinal segment - Colectomy (partial or complete) - Proctocolectomy - Unlike UC, CD cannot be cured with surgery 	<ul style="list-style-type: none"> - Proctocolectomy (removal of the colon and rectum) <ul style="list-style-type: none"> - With ileostomy - Restorative (ileoanal or J pouch) - Disease is "cured" once the colon is removed 	<ul style="list-style-type: none"> - Alleviate complications - Alleviate symptoms - Achieve best possible quality of life - Bowel conservation

Restorative proctocolectomy – *Proctocolectomy* involves the surgical removal of both the colon and rectum. A restorative proctocolectomy, also called an ileoanal pouch anal anastomosis (IPAA or J pouch), is a newer procedure that allows the patient to continue to pass stool through the anus. The procedure can be performed in one, two, or three stages, although it usually is performed in two. This procedure has become the most commonly performed surgical procedure for ulcerative colitis.

Proctocolectomy with ileostomy – In the traditional proctocolectomy procedure, the colon, rectum, and anus are removed, and an ileostomy is created. This surgery is done for ulcerative colitis or Crohn's disease of the colon when all medications have failed. An *ileostomy*—performed after the proctocolectomy—involves bringing the end of the small intestine (ileum) through a hole (stoma) in the abdominal wall, allowing drainage of intestinal waste out of the body. The stoma is usually created in the right lower abdomen near the belt line. After the procedure, an external bag must be worn over the opening at all times to collect waste.

Strictureplasty – This procedure is used when Crohn's disease affects the small intestine and areas of active disease may narrow, forming *strictures* that can block the passage of digested food. This procedure widens the strictured area without removing any portion of the small intestine.

Resection – In this procedure, a segment of the small intestine is removed and the two ends of healthy intestine are joined together (*anastomosis*). Also called small bowel resection, it may be required if a hole develops in the wall of the small intestine.

When making the decision to have surgery, it's helpful to understand why you may need surgery, to educate yourself about the different surgical options, and to ask questions of your healthcare team. You also may want to speak with individuals who have undergone the procedure you are considering.



Have you considered surgery? Is it something you would be comfortable with as an elective procedure or only if it were absolutely necessary?

Let's talk about other types of treatment.

Complementary and alternative medicine or CAM encompasses a large array of treatment options. The National Center for Complementary and Alternative Medicine (NCCAM) defines CAM as a group of diverse medical and healthcare systems, practices, and products that are not presently considered part of conventional medicine. While scientific evidence exists regarding some CAM therapies, for the most part, well-designed scientific studies to answer questions, such as whether these therapies are safe and whether they work for the purposes for which they are used, have not been conducted.

Complementary therapies are intended to be used together with conventional treatment, while the term "alternative" implies replacing the treatment you receive from your doctor with one or more approaches that fall outside mainstream medicine. CCFA recommends that individuals who are considering any of the CAM approaches discuss them with their doctor.



CAM therapies may work in a variety of ways. They may help to control symptoms and ease pain, enhance feelings of well-being and quality of life, and may possibly boost the immune system. The NCCAM divides CAM into four major domains:

- 1 Mind-body medicine** is a set of interventions that focus on the interplay between emotional, mental, social, spiritual, and behavioral factors and their influence on health. Examples include prayer, tai chi, hypnosis, meditation, biofeedback, and yoga.
 - 2 Manipulative and body-based practices** involve manipulation or movement of one or more parts of the body as a means of achieving health and healing. Examples include chiropractic and osteopathic manipulation, massage, and reflexology.
 - 3 Energy medicine** draws on a number of traditions supporting the view that illness results from disturbances of subtle energies. *Biofield therapies* involve the application of pressure or the placement of hands in or through these energy fields and include Reiki, qi gong, and therapeutic touch. *Bioelectromagnetic-based therapies* utilize electromagnetic fields for the purposes of healing and include magnetic therapy, sound energy therapy, and light therapy.
 - 4 Biologically-based practices** utilize substances found in nature, such as herbs, foods, and vitamins to strengthen, heal, and balance the body. Examples include dietary supplements, probiotics, prebiotics, herbal products, fatty acids, amino acids, and functional foods. These substances should only be taken with the approval of your doctor along with a doctor's prescribed medication.
- ? Have you taken or considered using a complementary or alternative treatment? If you are interested, be sure to discuss it with your doctor.**

More on probiotics and supplements

Probiotics are live bacteria that are similar to beneficial (often called “good” or “friendly”) bacteria that normally reside in the intestines. Under normal circumstances, beneficial bacteria keep the growth of harmful bacteria in check. If the balance between good and bad bacteria is thrown off, causing harmful bacteria to overgrow, diarrhea and other digestive problems can occur. Probiotics are used to restore the balance of these “good” bacteria in the body. They are available in the form of dietary supplements (capsules, tablets, and powders) or foods (yogurt, milk, miso, tempeh, and some beverages).

There is some evidence to suggest that use of probiotics may help people with IBD to maintain remission. Scientific studies have also shown that they may be useful for preventing and treating pouchitis. Taking probiotics is generally safe and any side effects (such as gas or bloating) are usually mild.

Vitamins are another supplement that may be helpful as some people with IBD may develop vitamin or mineral deficiencies that require supplementation for a variety of reasons. These include:

- Vitamin B-12 (to combat deficiency)
- Folic acid (to combat deficiency)
- Vitamin D (to combat deficiency)
- Calcium (to combat deficiency and bone loss from certain medications)
- Iron (to combat deficiency, known as anemia)

If you have any questions or concerns regarding potential deficiencies, be sure to talk your doctor.

We hope this week’s material on the medical management of IBD has been informative. In preparation for this week’s live online support group session, consider the following:

- What did you learn from this material?
- What do you still want to learn?
- Are you apprehensive about the possibility of needing surgery?
- Do you have a clear understanding of your treatment?

Next time we will address Diet and Nutrition, including the role of diet in IBD, the impact of certain foods, tips for eating well for IBD when experiencing a flare up, as well as vitamin usage.

Additional Resources

CCFA offers many resources and services to provide you with accurate, current, disease-related information. Check out the resources below for more information on living well with IBD.

CCFA's Information Resource

Center (IRC) is a support line for patients and caregivers living with IBD. We can help guide you in the right direction—whether you need to locate a doctor, find financial resources, or have questions about your disease. Specialists are available Monday-Friday, 9 AM to 5 PM Eastern time. Call 1-888-MYGUTPAIN (1-888-694-8872) or email info@ccfa.org.

CCFA's website (www.ccfa.org)

is a great place to continue your research on IBD and connect with your local chapter to learn more about programs in your area.

Additionally, you can:

- View free educational webcasts on a variety of topics at www.ccfa.org/resources/webcasts.html.
- Visit www.IBDetermined.org to learn more about IBD through videos, interactive quizzes, and more!
- Download pertinent brochures at www.ccfa.org/resources/, including:
 - Understanding IBD Medication and Side Effects
 - Surgery for Crohn's Disease and Ulcerative Colitis
 - Complementary and Alternative Medicine (CAM)