

# ONLINE Support Group

Week 2: Medical Management



## Welcome to the Crohn's & Colitis Foundation's Online Support Group for Caregivers

Last week's material provided 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 medications, surgery, and complementary/alternative options.

### Treatment goals

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 achieved through the creation and use of a comprehensive *IBD Management Plan* which should be designed to:

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

An effective *Management Plan* will ensure that IBD has the smallest possible impact on your loved one's quality of life. A plan should include such things as medications, nutritional therapies, surgery, social support, and/or lifestyle changes.



You and/or your loved one should work **together** with the doctor to create a plan that meets your loved one's specific needs.

Even for those in long-term remission, these diseases can flare without warning. Thus, understanding IBD and how it can affect your loved one is central to controlling the disease and to developing an approach that is positive and adaptable to changing situations.



- *Are your loved one's symptoms being managed?*
  - *Do you feel your loved one's quality of life has improved since treatment started?*
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## Prescription medication

While there are many medications available to help control IBD, there is no single ideal medication. Everyone's disease is different, so everyone's disease is treated differently. Therefore, you and/or your loved one need to work **with** your doctor to select a medication that meets your loved one's specific needs. For this reason, it's very important for you to have a full understanding of all available medication options as well as their risks and benefits.

Five different categories of medications are used to treat IBD, both for children and adults. These treatment categories include:

1. **Aminosalicylates:** These medications help control inflammation by delivering a compound containing 5-aminosalicylic acid (5-ASA) to the intestine 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 the return of symptoms (*disease relapse*). These medications are generally very well tolerated and have few side effects.
2. **Corticosteroids:** These medications are used to treat those with moderate-to-severe IBD. They can be taken orally, rectally, or through a vein (*intravenously*). They can be very effective when your loved one is experiencing a disease flare, but it is not recommended that they be taken for long periods of time (greater than a few months) because they can have serious side effects. Some side effects include weight gain, insomnia, mood swings, osteoporosis, stunted growth in children, hair loss, and acne. They may also make it more likely for you to get an infection or to bruise easily.
3. **Immunomodulators:** These medications 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. **Biologics:** These therapies are genetically engineered to target very specific molecules involved in the inflammatory process. 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 of intestine to another or two organs in the body that are usually not connected.)

5. **Antibiotics:** These medications may be used when infections—such as an *abscess*—occur. They can be used to treat Crohn’s disease, ulcerative colitis, and perianal Crohn’s disease. They are also used for post-surgical problems, such as *pouchitis* (a condition that can follow surgery when the colon is removed and a j-pouch is created).

It is important for you and/or your loved one to consult with your doctor and discuss thoroughly which course of therapy is best—bearing in mind that a combination of therapies may be the optimal treatment plan.

Some key medication takeaways include the following:

- **Weigh the pros and cons.** Even though a medication may have a chance of causing side effects, the potential benefits may outweigh the risks.
- **Take medications as prescribed.** Taking medications as prescribed can significantly reduce the risk of developing future disease flares and complications.
- **Strive for no symptoms.** Your loved one should strive to live a life without symptoms. Therefore, you and/or your loved one should let the doctor know if your loved one is still experiencing symptoms while on medications. During these discussions, you and/or your loved one should feel comfortable asking the doctor about other available medication options.
- **Things may change.** Your loved one’s medication may need to change over time. What works at one point during your loved one’s disease may not be effective at another stage.

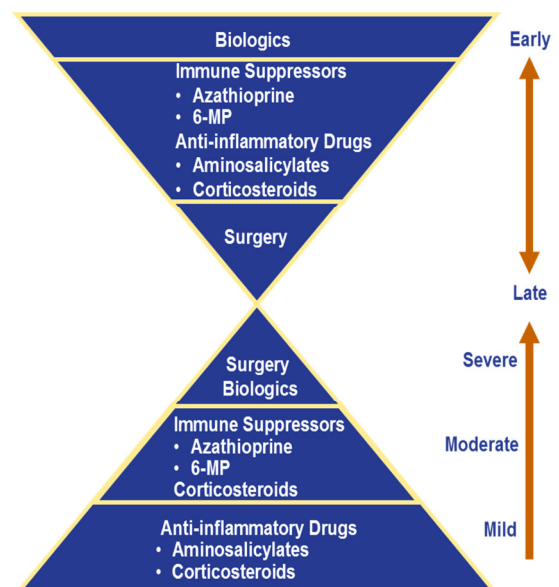


*Have you and/or your loved one discussed all treatment options, including benefits and risks, with the healthcare team?*

## Treatment Strategies

There are two strategies used when selecting a treatment plan:

**Bottom-Up (or Step-Up)** is a more traditional approach and may be appropriate for many patients (see bottom pyramid on image to the right). This strategy often starts with medications that may be less effective but potentially have fewer side effects, such as aminosalicylates and antibiotics. If these medications do not work, then the patient is given a medication that may be more effective but potentially has more side effects, such as immunomodulators or biologics.



However, patients with moderate-to-severe disease upon diagnosis may benefit from earlier, more aggressive treatment (such as immunomodulators or biologics).

**Top-Down** is an approach that uses more aggressive treatments earlier, such as biologics (see top pyramid on image on previous page). This approach can potentially minimize steroid use (and their associated side effects), heal the lining of the intestine, prevent future complications, and may help to avoid surgery. However, patients taking these medications may have more side effects and infections.

Before selecting a treatment strategy, you and/or your loved one should discuss the benefits and risks of each approach with the doctor – and make the decision **together**.



*Do you know what treatment strategy your loved one is receiving?*

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## Other Medications

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

When it is appropriate, the doctor may recommend over-the-counter medications to relieve diarrhea or anti-gas products for bloating. To reduce joint pain and fever, the doctor may recommend acetaminophen (such as Tylenol) or a non-steroidal anti-inflammatory drug (NSAID), such as aspirin, ibuprofen, or naproxen. However, NSAIDs should be used carefully because they can irritate the lining of the intestines and cause intestinal inflammation.

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## Surgical Options

The decision to have surgery to help manage a patient's IBD 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 some details on the most common surgeries.

- **Strictureplasty:** This procedure may be used when areas of the small intestine are inflamed and become very narrow (forming *strictures*), which can block digested food from passing through. This procedure widens the narrowed area without removing any portion of the small intestine.

### Primary goals of surgery

- Alleviate complications
- Alleviate symptoms
- Achieve best possible quality of life
- Bowel conservation

- **Resection:** In this procedure, a damaged segment of the small intestine is removed and the two ends of healthy intestine are joined together (*anastomosis*).
- **Proctocolectomy with ileostomy:** In the traditional proctocolectomy procedure, the colon, rectum, and anus are removed, and an ileostomy is created. This surgery is most often 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 the waste.
- **Restorative proctocolectomy:** A 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.

When making the decision to have surgery with the doctor, it's helpful to:

- Thoroughly understand why your loved one may need surgery
- Educate yourself and your loved one about the different surgical options
- Ask questions of the healthcare team
- Speak with individuals who have undergone the procedure your loved one is considering



- *Has your loved one considered surgery?*
- *Is it something your loved one would be comfortable with as an elective procedure or only if it were absolutely necessary?*

## Complementary and Alternative Therapy

**Complementary and alternative medicine (CAM)** is defined as a group of medical and healthcare systems, practices, and products that are not presently considered part of conventional medicine.

While some CAM therapies have been studied and show potential benefits, most CAM therapies have not been thoroughly studied (such as whether these therapies work or are safe) in IBD.

Complementary therapies are intended to be used together with conventional treatment. The Crohn's & Colitis Foundation recommends that individuals who are considering using a CAM therapy should first discuss it 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 boost the immune system. CAM therapies mainly fall into four categories:

1. **Mind-body medicine** focuses on the emotional, mental, social, spiritual, and behavioral factors that can influence 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** supports 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* use 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 a doctor along with a doctor's prescribed medication.



- *Has your loved one ever taken or considered using a complementary or alternative treatment?*
- *If they are interested, be sure to have them discuss it with the doctor first.*

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## This week's online support group

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 or your loved one apprehensive about the possibility of needing surgery?
- Do you have a clear understanding of your loved one's 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.

To join this week's support group, visit: <http://ccfacommunity.org/chatseries.aspx>

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# Crohn's & Colitis Foundation Resources

The Crohn's & Colitis Foundation offers many resources and services to provide you with accurate and current disease-related information. Check out the resources below for more information on living well with IBD:

- **IBD Help Center** 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 Standard Time (EST). Call 1-888-MY-GUT-PAIN (1-888-694-8872) or email [info@ccfa.org](mailto:info@ccfa.org).
- **Crohn's & Colitis Foundation Website** ([www.ccfa.org](http://www.ccfa.org)) is a great place to continue your research on IBD. Additionally, you can:
  - View free educational videos and webcasts
  - Download free brochures and fact sheets
  - Connect with your local chapter
  - Find ways to get involved