



Inflammatory Bowel Disease (IBD)

Inflammatory Bowel Disease (IBD) Overview



<u>More</u>

Ulcerative Colitis



The American College of Gastroenterology wants to help patients understand that UC is a treatable condition that can be

managed effectively. <u>Learn More</u>

What You Should Know



Ulcerative colitis (UC) is a disease marked by inflammation of the lining of the colon and rectum, together known as the large intestine.

Learn more



Crohn's disease (CD) is a chronic disease that can cause inflammation anywhere from the mouth to the anus anywhere along the lining of

the digestive tract. It most commonly affects the small intestine and the colon. Learn more

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Children and teens with IBD face unique challenges. Dr. Marla C. Dubinsky sheds light on these challenges, including the psychological aspects and offers tips for parents. <u>Listen Now</u>

IBD Overview

• What is the difference between Ulcerative Colitis and Crohn's Disease?

Ulcerative colitis and Crohn's disease are two types of Inflammatory Bowel Disease (IBD). The large intestine (colon) is inflamed in ulcerative colitis, and this involves the inner lining of the colon. In Crohn's disease the inflammation extends deeper into the intestinal wall. Crohn's disease can also involve the small intestine (ileitis), or can involve both the small and large intestine (ileocolitis).

• How is IBD different from Irritable Bowel Syndrome?

IBD develops due to inflammation in the intestine which can result in bleeding, fever, elevation of the white blood cell count, as well as diarrhea and cramping abdominal pain. The abnormalities in IBD can usually be visualized by cross-sectional imaging (for instance a CT scan) or colonoscopy. Irritable Bowel Syndrome (IBS) is a set of symptoms resulting from disordered sensation or abnormal function of the small and large bowel. Irritable Bowel Syndrome is characterized by crampy abdominal pain, diarrhea, and/or constipation, but is not accompanied by fever, bleeding or an elevated white blood cell count. Examination by colonoscopy or barium x-ray reveals no abnormal findings.

• What is the cause of IBD?

There is no single explanation for the development of IBD. A prevailing theory holds that a process, possibly viral, bacterial, or allergic, initially inflames the small or large intestine and, depending on genetic predisposition, results in the development of antibodies which chronically "attack" the intestine, leading to inflammation. Approximately 10 percent of patients with IBD have a close family member (parent, sibling or child) with the disease, which lends support to a genetic predisposition in some patients.

• Is IBD caused by stress?

Emotional stress due to family, job or social pressures may result in worsening of the Irritable Bowel Syndrome but there is little evidence to suggest that stress is a major cause for ulcerative colitis or Crohn's disease. Although IBD is not caused by stress recent studies show that there may be a relationship between the two--stressful periods in life may lead to a flare of disease activity in persons with the underlying diagnosis of IBD.

• How is IBD diagnosed?

There is no single test that can make the diagnosis of IBD or completely rule out its existence reliably. Colonoscopy, cross-sectional imaging studies of the colon or the upper GI tract, along with newer blood tests that detect markers that are commonly associated with IBD, along with a patient's history and physical exam, can all be useful in helping your doctor establish a diagnosis of IBD.

• What are the complications of IBD?

Ulcerative colitis and Crohn's disease can lead to diarrhea, bleeding, anemia, weight loss, fevers, malnutrition and fistulae. IBD can also have extraintestinal manifestations where areas other than your gastrointestinal system such as your skeletal system, your skin or your eyes may be involved.

• <u>Is diet management important for patients with IBD?</u>

Physicians prefer to maintain good nutrition for those diagnosed with IBD. If you are responding well to medical management you can often eat a reasonably unrestricted diet. A low-roughage diet is often suggested for those prone to diarrhea after meals. If you appear to be milk sensitive (lactose intolerant), you are advised to either avoid milk products or use milk to which the enzyme lactase has been added.

• How successful is medical therapy?

With early and proper treatment the majority of patients with IBD lead healthy and productive lives. Some patients may require surgery for treatment of complications of IBD such as an abscess, bowel obstruction or inadequate response to treatment.

What are surgical options for IBD?

Crohn's disease of the small or large intestine can be treated surgically for complications such as obstruction, abscess, fistula or failure to respond adequately to treatment. The disease may recur at some time after the operation.

Ulcerative colitis is curable with removal of the entire colon. This may require creating an "ileostomy" (with attachment of the ileum to the external abdominal wall with an external application pouch) or may involve the direct attachment of the small intestine (ileum) to the anus. This type of surgery, known as "IPAA surgery," does not require an external application pouch

Crohn's Disease

If you have persistent symptoms such as diarrhea and abdominal pain or cramps, it could be Crohn's disease. A chronic disorder, Crohn's disease may cause you to have a wide-range of digestive symptoms that may be mild or severe and may flare up over time.

• What is Crohn's disease?

Crohn's disease belongs to a group of conditions known as inflammatory bowel disease (IBD). Crohn's disease is a chronic disorder that can cause inflammation anywhere along the digestive tract from the mouth to the anus (end of the large intestine).

Although Crohn's disease usually occurs in the last part of the small intestine (called the ileum) and the beginning of the colon (the cecum i.e., the large intestine), it can develop in patches or involve anywhere along the digestive tract. The inflammation caused by Crohn's disease can penetrate through the outer layer of the lining into deeper layers and even penetrate into adjacent organs. When this occurs, the "tunnel" that develops is called a fistula.

What is the outlook for people with Crohn's disease?

Although Crohn's disease doesn't have a cure, most people who have the disorder function well with proper treatment. The symptoms can come and go, with long periods of remission before symptoms flare up again, but it is important to know that many patients who have no symptoms still have active inflammation that may progress and cause bowel damage. Therefore, it is important to monitor the amount of inflammation in the bowel in order to manage the disease most effectively. For the best possible health and quality of life, visit your doctor regularly for checkups to monitor for symptoms and complications.

Women who have Crohn's disease can become pregnant and have healthy pregnancies, deliveries, and babies. Well-managed Crohn's disease does not increase the risk of miscarriages, stillbirths, or congenital conditions.

If you have Crohn's disease and become pregnant, talk with your doctor. It is recommended that you speak with your gastroenterologist prior to becoming pregnant to avoid potential complications to you or your baby. The treatment goal during pregnancy is to prevent and treat flare-ups aggressively to minimize any risk to the unborn baby.

• What are the signs and symptoms of Crohn's disease?

Signs and symptoms can range from mild to severe and vary depending on the part of the digestive tract affected. Symptoms usually develop over time but can occur suddenly.

The most common symptoms of Crohn's disease are:

- Diarrhea
- Pain and cramping in the abdomen (belly)
- Fatigue
- Feeling the need to have a bowel movement
- Fever
- Weight loss

Other symptoms may include:

- o Blood in the stool
- Drainage around the anus caused by inflammation
- Joint pain
- Loss of appetite
- Nausea and vomiting
- o Pain, redness, or swelling in the eyes
- Rashes

• When should I see a doctor about Crohn's disease?

The signs and symptoms of Crohn's disease can be similar to those of other conditions. If you have any symptoms, or changes in your bowel habits that persist, see your doctor for an evaluation.

What causes Crohn's disease?

Although medical experts don't know the exact causes of Crohn's disease, they think certain factors could be involved, such as:

- **Autoimmune response:** A virus or bacterial infection might trigger Crohn's disease, and an abnormal immune reaction causes the immune system to attack cells in the lining of the digestive tract.
- o Genes: People who have a family member with Crohn's disease are more likely to develop the disease.
- Environmental factors

What are the risk factors for Crohn's disease?

Risk factors for Crohn's disease can include:

- Age: Most people are diagnosed with the condition between ages 20 and 29, although it can occur at any age.
- Family history: If you have one parent with Crohn's disease, your lifetime risk of developing the disease is approximately 7 to 10 percent. If both parents have the disease, your lifetime risk increases to 35 percent.
- Nonsteroidal anti-inflammatory drugs (NSAIDs): Medications such as ibuprofen, naproxen sodium, and others do not cause Crohn's
 disease but can worsen inflammation and cause the disease to flare in people who already have the condition.
- Race and ethnicity: White people and people of Eastern European Jewish (Ashkenazi Jewish) descent are at the highest risk.
- Smoking: Tobacco use doubles the risk of Crohn's disease and increases the likelihood of having a more severe form of the disease and requiring surgery.
- o Location: People who live in industrialized countries and urban areas are also at elevated risk of developing Crohn's disease.
- Antibiotics
- o Infections (GI)

• Who should be evaluated for Crohn's disease?

See your doctor if you have any of the signs, symptoms, or risk factors for Crohn's disease. Your doctor will perform an exam and testing to evaluate for the presence of other similar conditions or confirm a diagnosis.

• How is Crohn's disease diagnosed?

Your doctor will discuss your symptoms, medical history and risk factors for Crohn's disease and conduct a physical exam to check for signs of the condition. Although no single test for Crohn's disease exists, a combination of tests can rule out other conditions and confirm a diagnosis.

Tests that you may need:

- Blood tests to check for signs of infection, anemia (low blood count), malabsorption and abnormal liver tests.
- Stool sample to check for blood in the stool and for infections that can simulate active IBD
- o CT or MRI scans to provide highly detailed images for closer evaluation

Doctors may also use diagnostic procedures such as:

- **Colonoscopy or flexible sigmoidoscopy:** Using a thin, flexible scope with a lighted camera, your doctor examines the inside of the colon and possibly the lower end of the small intestine (colonoscopy).
- Biopsy: Your doctor may perform this procedure during a colonoscopy, taking a small tissue sample for evaluation under a microscope.
- Upper endoscopy: Also called an esophagogastroduodenoscopy (EGD), this procedure examines the upper part of the digestive tract.
- Capsule endoscopy: You swallow a capsule containing a tiny camera that takes pictures of the digestive tract and transmits the images to a computer for your doctor to examine.
- CT scans or MRI imaging: these imaging tests may be used to better characterize the amount of small intestine or other parts of the
 abdominal organs that may be inflamed
- Barium x-rays: although not used as often any more, this test involves drinking a liquid or having it administered by enema that will allow x-rays to show how the bowel is shaped and looks.
- What are the treatments for Crohn's disease?

Currently, there is no cure for Crohn's disease, and treatments work differently in different people. The goal of treatment is to relieve symptoms, heal the inflammation within the bowel, prevent complications, and improve your quality of life.

Doctors typically begin your treatment plan with medications to bring symptoms under control. Then you receive treatment aimed at maintaining remission and reducing the frequency of flare-ups.

Medications

Your doctor may use one or more medications such as:

- **Antibiotics:** These medications can reduce drainage and heal abscesses. They may also help reduce harmful bacteria in the intestines that might be stimulating the immune system.
- Steroids: Corticosteroids can reduce inflammation throughout the body by suppressing the entire immune system. There is also a steroid called budesonide that works primarily in the bowel and does not affect the rest of the immune system.
- Immunosuppressant medications: These medications reduce the body's immune response to reduce inflammation and allow the intestinal tissue to heal
- Biologic therapies: These medications block the body's immune response. Doctors typically use biologic therapies to treat moderate to severe Crohn's disease.

Nutrition therapy

- In children, specialized liquid diets have been shown to have some benefit in treating Crohn's disease, but these are difficult to tolerate so are usually administered through a tube. This approach to management is not sustainable for most people.
- Some patients with Crohn's disease may need temporary intravenous nutrition (fluid nutrition injected through a vein) and bowel rest. This is reserved for more severe cases.

Surgery

If other treatments do not effectively relieve your symptoms, or if disease-related complications present (such as a stricture [narrowing of the bowel] or a precancer or cancer arises in the bowel), surgery can provide a temporary solution. Surgery does not cure Crohn's disease. The surgeon removes the damaged/abnormal portions of the digestive tract and reconnects the healthy sections. About half of the people with Crohn's disease need surgery to control symptoms over the course of their lifetime.

Alternative medicine

Complementary and alternative medicine (CAM) therapies, such as acupuncture, fish oil, or nutritional supplements, have not shown significant benefit for treating Crohn's disease.

Am I at risk of developing other conditions?

People with Crohn's disease can develop complications related to the condition or may experience side effects from their medications. Some common complications include:

- Anal fissures: A tear in the tissue lining the anus or in the skin around the anus, which can cause painful bowel movements, blood in the stool, and sometimes localized itching of the anus.
- Ulcers: These open sores in the digestive tract, including the mouth, genital area and anus, can result from chronic inflammation.
- **Fistulas:** If ulcers extend through the intestinal wall, an abnormal tunnel between different areas can develop. Fistulas can lead to drainage, infections, and diversion of food, which can prevent you from getting enough nutrients.
- Bowel obstruction: Long-term inflammation can cause scar tissue to form, which can thicken and narrow areas of the bowel, blocking the flow
 of digestive contents. Medications can reduce inflammation and open up the narrowed areas, but some people require surgery to remove the
 diseased portion of the bowel.
- **Malnutrition:** Symptoms of Crohn's disease, such as diarrhea, abdominal pain, and abdominal cramping, may make eating difficult. Intestinal inflammation can prevent proper absorption of vital nutrients needed to maintain a state of good health.
- Colon cancer: Crohn's disease that affects the colon increases the risk of developing colon cancer. People with Crohn's disease should have
 colonoscopies more frequently than people without risk factors. In certain situations, your physician may want to spray a dye in the bowel (this
 is called "chromoendoscopy") during your colonoscopy to better see lesions.
- What are some recommendations for living with Crohn's disease?

If you have Crohn's disease, healthy lifestyle habits can help you maintain a good quality of life. Talk to your doctor about:

Healthy eating plan: Certain changes can help reduce symptoms, but it's important to understand that symptom management does not
mean that the inflammation is under control. A healthy eating plan should be accompanied by appropriate measures to make sure it is

nutritious (that you are receiving the nutrition you need), and that your inflammation is being measured and monitored to make sure the treatments are achieving their goals:

- Eat nutritious foods
- Drink more liquids
- Avoid carbonated (fizzy) drinks
- Avoid excessive high-fiber foods such as popcorn, vegetable skins, or nuts
- Avoid fatty, fried foods, or fast foods.
- Take vitamins (such as vitamin D or vitamin B12) or other nutritional supplements, if recommended by your doctor
- Exercise: Make time for regular physical activity each day. Exercise can be as simple as walking for 10 to 20 minutes per day and can help relieve stress and minimize symptoms.
- o Smoking cessation: Quitting smoking reduces your risk of health complications due to Crohn's disease.

Ulcerative Colitis

• What is Ulcerative Colitis?

Ulcerative colitis (UC) is a disease marked by inflammation of the lining of the colon and rectum, together known as the large intestine. This inflammation causes irritation in the lining of the large intestine which leads to the symptoms of UC.

Though UC always affects the lowest part of the large intestine (the rectum), in some patients it can be present throughout the entire colon. UC belongs to a group of diseases called inflammatory bowel diseases which also includes Crohn's disease (CD). Though it was once thought that UC and CD were two different diseases, as many as 10% of patients may have features of both diseases and this is called IBD-U (IBD-Unclassified). It is important to note that inflammatory bowel disease (IBD) is different from irritable bowel syndrome (IBS).

• What are the symptoms of UC?

The symptoms of UC depend on the severity of inflammation and the amount of the colon that is affected by the disease.

In patients with mild to moderate inflammation, symptoms can include:

- o rectal bleeding,
- o diarrhea,
- o mild abdominal cramping,
- o stool urgency, and
- tenesmus (discomfort and the feeling that you have not completely emptied your rectum after a bowel movement).

When more severe inflammation is present, patients often develop:

- fever.
- dehvdration.
- o severe abdominal pain,
- o weight loss,
- o loss of appetite or
- o growth retardation (in children and adolescents with UC).
- Individuals with moderate or severe inflammation may also have to wake up at night to have bowel movements and may lose control of bowel
 movements.

Some of the symptoms of UC may be non-specific and could be caused by other diseases such as Crohn's disease, irritable bowel syndrome, or infection. Your doctor can help determine the cause of your symptoms and should be consulted should you experience a significant change in your symptoms.

How is UC diagnosed?

Your doctor will usually suspect the diagnosis of UC based on your symptoms, but confirmation of the diagnosis requires testing.

- **Blood work** is often checked to look for markers of inflammation or anemia (low blood counts), though these tests can be normal in patients with mild disease.
- Tests of your stool to look for evidence of an intestinal infection are often obtained.
- Radiologic images including x-rays and CT scans are usually not recommended but may be performed.

What endoscopic tests are used to diagnose UC?

All patients with symptoms consistent with UC should have a **colonoscopy** or **flexible sigmoidoscopy** to confirm the diagnosis, assuming that they are healthy enough to undergo the procedure. During this procedure, your gastroenterologist will be able to directly examine the lining of your colon and rectum to look for evidence of inflammation and take small biopsies to be examined under a microscope to look for the cause of the inflammation.

What causes UC?

The way in which patients get UC is still poorly understood.

Causes may include an interaction between:

- o the unique genetic makeup of an individual,
- o environmental factors, and
- o a patient's specific immune system that triggers the disease.

• What is known about risk factors for UC?

- UC is not an infection that can be passed from person to person.
- o Men and women are equally affected by UC.
- UC is more common in first degree relatives (siblings, parents, and children) of patients affected by UC and up to 10% of patients will have an
 affected family member. Despite the influence of genetics, the majority of patients with UC do not pass the disease to their children. There is
 no way to predict those at higher risk.
- Cases of UC have been identified throughout the world though certain populations, including those living in Northern climates and those of Jewish descent, are at higher risk of developing UC.
- Individuals having their appendix removed prior to the age of 20 appear to be at lower risk of developing UC.

- No specific infectious agent has been linked to UC. Diet, breast feeding, and various medications have also been examined, but none have been found to cause UC.
- It has been observed that some patients develop UC when they quit smoking, and current smokers have lower rates of UC than non-smokers. Furthermore, those who smoke and have UC tend to have a milder course of UC than those who do not smoke (note that this is the exact opposite effect that smoking has on Crohn's disease). Despite the protective role smoking appears to have on the development and natural history of UC, it is not recommended that patients start smoking to prevent UC due to the fact that there are so many other illnesses and cancers in which smoking is a definite risk factor.
- What are the possible complications of UC?

The complications of UC can be divided into those affecting the colon and those occurring outside of the colon.

• What are the complications of UC within the colon?

Within the colon, UC can rarely lead to colon cancer or toxic megacolon (a rare but potentially lethal widening of the large intestine).

• What is the risk of Colon Cancer in UC?

UC is known to increase the risk of colon cancer. Those patients who have had UC for a long time and those with a longer length of the colon affected are at higher risk of developing colon cancer. In general, patients begin to have an increased risk of colorectal cancer 8 years after the onset of disease symptoms and should have colonoscopy every one or two years starting at this time.

Colon cancer is a rare complication and it is thought that it may be preventable based on control of inflammation of the colon and careful colonoscopy examinations that look for any pre-cancerous changes called dysplasia. Overall, the risk of colon cancer increases 0.5 percent yearly after ten years of disease though patients with inflammation throughout their colon may be at higher risk.

Those patients with primary sclerosing cholangitis (PSC) are at greatest risk for colon cancer and need to start screening upon diagnosis.

What are the risks outside of the colon in UC patients?

Patients with UC are also at risk for extra-intestinal manifestations of UC (complications outside of the colon). These complications most frequently involve the liver, skin, eyes, mouth, and joints.

What are the complications within the liver in UC patients?

Within the liver, patients with UC may develop <u>primary sclerosing cholangitis</u>. This occurs in about 3% of patients with UC. PSC can progress even if UC is not active and it is often detected by elevations in liver blood tests and confirmed by the use of MRI scans such as Magnetic Resonance Cholangiopancreatography (MRCP) or endoscopic procedures such as Endoscopic Retrograde Cholangiopancreatography (ERCP).

What rashes can appear UC patients?

Patients with UC can develop sores in the mouth or rashes on the skin that generally only appear when UC colon symptoms are active. The most common rashes that are seen in UC are erythema nodosum (EN) and pyoderma gangrenosum (PG).

- e EN usually presents as a red, raised, painful area most commonly on the legs and is most often seen during flares of UC.
- PG also presents as raised lesions on the skin (most frequently on the legs) that often develops after trauma to the skin and can lead to the
 formation of ulcers. Unlike in EN, the appearance of skin lesions in PG may or may not mirror the activity of bowel symptoms. The eyes can
 become red and painful (uveitis) and vision problems should be reported to your doctor.

• How does UC affect the joints in in UC patients?

Arthritis is commonly associated with UC and can affect either small (such as the fingers/toes) or large joints (often the knee), though involvement of the smaller joints may have a course that is not related to activity in the colon. The joints of the spine can be affected as well, though this is less common than it is in Crohn's disease.

What are mood problems that may impact UC patients?

As in other chronic medical conditions, anxiety and depression are common in patients with UC. The unpredictability of UC and the need to take medications on a daily basis can lead to feelings of frustration or anger. Though occasional feelings of frustration can be normal, feelings of significant anxiety or depression should be brought to the attention of your physician. There are many support opportunities available for those having trouble coping with UC (see the final section).

What is the clinical course of UC?

UC can present in a variety of ways. UC is often a chronic, life-long condition. It most often is diagnosed in the 2nd and 3rd decades of life (ages 11 to 30), although it can be diagnosed at any age. The initial presentation can be mild and is sometimes confused with other conditions such as irritable bowel syndrome or it can be very severe and require hospitalization and surgery.

For most patients, UC tends to follow a course marked by periods of disease activity followed by variable periods during which a patient is symptom free. Some patients may have continuous disease activity. Rarely, a patient will have only a single disease flare.

In general, those people with a severe first attack of UC and those who have their entire colon affected by UC tend to have a more aggressive course with more frequent flares and shorter periods of remission. Despite the chronic nature of UC, most patients are able to function well and the life expectancy of a patient with UC is normal.

• How is UC treated?

Medical treatment of UC generally focuses on two separate goals:

- the induction of remission (making a sick person well), and
- the maintenance of remission (preventing relapse).

Surgery is also a treatment option for UC and will be discussed separately. Medication choices can be grouped into four general categories:

- o aminosalicylates,
- o steroids.
- o immunomodulators, and
- o biologics.

Aminosalicylates are a group of anti-inflammatory medications (sulfasalazine, mesalamine, olsalazine, and balsalazide) used for both the induction and maintenance of remission in mild to moderate UC. These medications are available in both oral formulations and rectal preparations (suppositories and enemas) and work on the lining of the colon to decrease inflammation. They are generally well tolerated. The most common side effects include nausea and rash. Rectal formulations of mesalamine (enemas and suppositories) are generally used for those patients with disease at the end of their colon.

Steroids (prednisone) are an effective medication for the induction of remission in moderate to severe UC and are available in oral, rectal, and intravenous (IV) forms. Steroids are absorbed into the bloodstream and have a number of severe side effects that make them unsuitable for chronic use to maintain remission. These side effects include cataracts, osteoporosis, mood effects, an increased susceptibility to infection, high blood pressure, weight gain, and an underactive adrenal gland.

Immunomodulators include medications such as 6-mercaptopurine and azathioprine. These are taken in pill form and absorbed into the bloodstream. They are effective for maintenance of remission in moderate to severe UC but are slow to work and can take up to two to three months to reach their peak effect. Because of this, these medications are often combined with other medications (such as steroids) in patients who are very ill. These medications require frequent blood work as they can cause liver test abnormalities and low white blood cell counts, both of which are reversible when the medication is stopped. Adverse reactions can include nausea, rash, liver and bone marrow toxicity, pancreatitis, and, rarely, lymphoma.

Biologic agents are medications given by infusion or injection that are used to treat moderate to severe UC. There are two classes of biological therapies that treat UC.

- First is the class of **anti-TNF therapies**. These antibodies target an inflammatory protein called "TNF" and have been shown to be effective for induction and maintenance of remission of UC. These include infliximab (Remicade®, Inflectra® and Renflexis®), adalimumab (Humira®) and golimumab (Simponi®). The side effects of these medicines may include an allergic reaction to the medication called a "hypersensitivity reaction." There are also rare risks of serious infections with these medications. Lymphoma is a rare risk of these therapies as well, but more recent scientific studies suggest that this may not be directly related to these medications, but instead primarily related to the thiopurine immune suppressants (see above.)
- The second class of biological therapy that treats UC is a medication that **blocks the body's ability to send white blood cells (part of your immune system) to the bowel and cause inflammation**. There is currently one therapy that is in this class (vedolizumab (Entyvio®), and it has been shown to induce and maintain remission of UC.

Tofacitinib is a more recently available oral medication (not a biological therapy) that also can induce and maintain remission of UC. Tofacitinib (Xeljanz®) works by blocking an enzyme that is responsible for turning on inflammation. This treatment can work quickly but may increase your cholesterol level or increase the risk of developing shingles infection (related to chicken pox). This risk can be minimized by having a vaccination for the shingles virus (varicella zoster).

As with all medications, you should discuss the risks and benefits with your doctor.

Other medications used less frequently for UC include cyclosporine and tacrolimus. These agents are sometimes used in those rare cases of severe UC that are not responsive to steroids. Side effects of these agents include infections and kidney problems. These agents are offered at a limited number of hospitals and are usually used for a short period of time as a bridge to other maintenance therapies such as azathioprine, 6-mercaptopurine or vedolizumab.

Taking Medication for UC as Prescribed: No matter which medical therapy you and your doctor decide upon, adherence with the prescribed course is essential. No medical therapy can work if it is not taken, and failure to take your medications can lead to unnecessary escalation of therapy if it is not brought to the attention of your doctor. Because many of the complications associated with UC are related to ongoing disease activity, good medication adherence may minimize these risks.

What is the role of surgery?

Surgery in UC is performed for a number of reasons and is generally considered to be curative if the entire large intestine is removed. Patients who do not respond to medications, are concerned about or have unacceptable side effects from medications, develop toxic megacolon, dysplasia (precancerous lesions) or cancer, or children who are not growing because of UC are often considered for surgery.

Several different surgeries are performed for UC and the choice of surgery is dependent on patient preference and the experience of the surgeon. The most common surgery is **total proctocolectomy with ileal pouch anal anastomosis** (total removal of the colon and rectum with creation of a pseudo-rectum from a portion of the small intestine). This is also sometimes called a "J pouch." This operation usually requires two separate surgeries to complete although it may require three stages in severely ill patients.

Following this surgery, patients can expect five to ten stools daily as they no longer have a colon to store stool. Patients usually feel better because their sense of stool urgency improves, they no longer have bleeding, and their medications can often be stopped. However, these patients are at risk for post-operative inflammation of the pouch known as pouchitis which is usually treated with antibiotics. Women who have this surgery may have decreased ability to get pregnant naturally.

Another common surgical procedure involves a **proctocolectomy with ileostomy** (removal of the entire colon and rectum and connection of the small intestine to the abdominal wall so that stool empties into a bag). This procedure is often undertaken in elderly patients, obese patients, or those with anal dysfunction. Should you need a surgical procedure for UC, your surgeon can help you decide which type of surgery best fits your needs.

Do complementary and alternative therapies work in UC?

Outside of the standard medical therapies discussed for UC, many alternative therapies have been studied. No studies have suggested that **diet** can either cause or treat UC and there is no specific diet that patients with UC should follow though it is advisable to eat a balanced diet. Likewise, there is no convincing evidence that UC results from food allergies. Though vitamin and mineral deficiencies are more common in Crohn's disease, specific deficiencies can occur in UC patients. For this reason, a multivitamin and a calcium supplement are not unreasonable.

Probiotics are species of bacteria that are proposed to have beneficial properties for the bowel. There are a number of scientific studies which have been performed to assess the role of probiotics in UC, and most of these have not shown benefit and therefore this is not usually recommended in UC.

Various other **herbal remedies and alternative therapies** have been studied for use in patients with IBD such as curcumin (a derivative of the herb turmeric) and parasitic worms (helminths). Though limited studies have shown promise for a number of alternative therapies, these have not yet been shown to be safe and effective and are not currently recommended.

What type of follow-up is required?

UC is a chronic disease and establishing a long-term relationship with a gastroenterologist experienced in the treatment of UC is advisable. Many medications used in UC require regular blood work to ensure that they are not causing any serious side effects. Patients with UC have a higher risk of osteoporosis associated with both underlying disease activity and long term or frequent steroid use. Because of this risk, your doctor may recommend measurement of Vitamin D blood levels and a bone mineral density screening with a DEXA scan. Colorectal cancer screening is also important because of the higher risk of cancer in patients with UC as discussed earlier.

Where can you get more information?

Many organizations provide support and information for patients with UC. The ACG Web site has additional information. The Crohn's and Colitis Foundation has extensive patient information along with links to various different social, financial, and medical support groups. Other sources of information include the individual drug company Web sites, and, most importantly, your personal physician.

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Ulcerative Colitis:

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IBD FAQs

• What is the difference between ulcerative colitis and Crohn's Disease?

Ulcerative colitis and Crohn's disease are two types of Inflammatory Bowel Disease (IBD). The large intestine (colon) is inflamed in ulcerative colitis, and this involves the inner lining of the colon. In Crohn's disease the inflammation extends deeper into the intestinal wall. Crohn's disease can affect any part of the bowel from the mouth to the anus.

• How is Inflammatory Bowel Disease different from Irritable Bowel Syndrome?

IBD develops due to inflammation in the intestine which can result in bleeding, fever, elevation of the white blood cell count, as well as diarrhea and cramping abdominal pain. The abnormalities in IBD can usually be visualized by cross-sectional imaging (for instance a CT scan) or colonoscopy. Irritable Bowel Syndrome (IBS) is a set of symptoms resulting from disordered sensation or abnormal function of the small and large bowel. Irritable Bowel Syndrome is characterized by diarrhea, crampy abdominal pain, and/or constipation, but is not accompanied by fever, bleeding or an elevated white blood cell count. Examination by colonoscopy or barium x-ray reveals no abnormal findings.

• What is the cause of IBD?

There is no single explanation for the development of IBD. A prevailing theory holds that a process, possibly viral, bacterial, or allergic, initially inflames the small or large intestine and, depending on genetic predisposition, results in the development of antibodies which chronically "attack" the intestine, leading to inflammation. Approximately 10 percent of patients with IBD have a close family member (parent, sibling or child) with the disease, which lends support to a genetic predisposition in some patients.

• Is IBD caused by stress?

Emotional stress due to family, job or social pressures may result in worsening of the Irritable Bowel Syndrome but there is little evidence to suggest that stress is a major cause for ulcerative colitis or Crohn's disease. Although IBD is not caused by stress recent studies show that there may be a relationship between the two--stressful periods in life may lead to a flare of disease activity in persons with the underlying diagnosis of IBD.

How is IBD diagnosed?

There is no single test that can make the diagnosis of IBD or completely rule out its existence reliably. Colonoscopy, cross-sectional imaging studies of the colon or the upper GI tract, along with newer blood tests that detect markers that are commonly associated with IBD, along with a patient's history and physical exam, can all be useful in helping your doctor establish a diagnosis of IBD.

What are the complications of IBD?

Ulcerative colitis and Crohn's disease can lead to diarrhea, bleeding, anemia, weight loss, fevers, malnutrition and fistulae. IBD can also have extraintestinal manifestations where areas other than your gastrointestinal system such as your skeletal system, your skin or your eyes may be involved.

What medical treatments are available for IBD?

Various formulations of 5-ASA, a drug which has been used to treat IBD for over 50 years, are available as oral preparations, suppositories and enemas. These are often one of the first drugs used to treat IBD.

Corticosteroid therapies, such as prednisone or hydrocortisone, are given when the 5-ASA products are insufficient to control inflammation. These drugs can be given orally, rectally as suppositories or enemas, or intravenously.

Drugs which suppress the body's immune response in IBD (known as immunomodulators) are used. Azathioprine and 6-mercaptopurine (6-MP) are the two most commonly used immunomodulators for anti-immune therapy.

Finally, a newer class of medications called "biologics" is used for patients with moderate to severe disease. Biologics include medications like infliximab (Remicade®), a medication given thru an IV infusion, and adalimumab (Humira®) and certolizumab pegol (Cimzia®), medications given via subcutaneous injection.

• Are there complications from the medical treatments?

Sulfasalazine, a 5-ASA product first used to treat IBD in the 1940s, may cause nausea, indigestion or headache in about 15 percent of patients and worsening diarrhea in about 4 percent of patients. The newer drugs have fewer side effects. Chronic corticosteroid therapy can lead to fluid retention and high blood pressure, some rounding of the face and softening of the bones similar to osteoporosis. These complications usually prompt attempts to discontinue corticosteroid treatment as soon as possible. The anti-immune drugs require periodic monitoring of the blood count since some patients will develop a low white blood cell count. These drugs, however, are usually well-tolerated in many patients. Biologics can alter a patient's ability to respond to any stressors to their immune system and in some patients may make it harder for their body to fight off infections.

• Is diet management important for patients with IBD?

Physicians prefer to maintain good nutrition for those diagnosed with IBD. If you are responding well to medical management you can often eat a reasonably unrestricted diet. A low-roughage diet is often suggested for those prone to diarrhea after meals. If you appear to be milk sensitive (lactose intolerant), you are advised to either avoid milk products or use milk to which the enzyme lactase has been added.

How successful is medical therapy?

With early and proper treatment the majority of patients with IBD lead healthy and productive lives. Some patients may require surgery for treatment of complications of IBD such as an abscess, bowel obstruction or inadequate response to treatment.

What are surgical options for IBD?

Crohn's disease of the small or large intestine can be treated surgically for complications such as obstruction, abscess, fistula or failure to respond adequately to treatment. The disease may recur at some time after the operation.

Ulcerative colitis is curable with removal of the entire colon. This may require creating an "ileostomy" (with attachment of the ileum to the external abdominal wall with an external application pouch) or may involve the direct attachment of the small intestine (ileum) to the anus. This type of surgery, known as "IPAA surgery," does not require an external application pouch

IBD Podcasts and Videos

ACG experts answer questions on topics of most concern to IBD patients, their caregivers and loved ones. With an emphasis on helping patients live well despite their IBD, the podcasts address reproduction and fertility; diet and nutrition; new and emerging therapies; the importance of clinical trials; and pediatric IBD.



Diet, Nutrition, and IBD - Sunanda V. Kane, MD, MSPH, FACG

- Is there a special diet for IBD?
- Nutritional challenges for IBD patients
- <u>Tips for Self-Management</u>



Fertility and Reproduction - Sunanda V. Kane, MD, MSPH, FACG

- Fertility and Reproduction
- <u>Pregnancy</u>



New and Emerging Therapies - William J. Sandborn, MD, FACG

- New and emerging therapies for IBD
- Outlook for individualized therapies



Pediatric IBD - Marla C. Dubinsky, MD

- Challenges Facing Children and Teens with IBD
- Does IBD Get Better or Worse as you Grow Up?
- Growth, Development and Body Image Concerns
- Psychological Aspects of IBD for Children and Teens
- Thriving with IBD
- Tips for Parents of a Child or Teen with IBD
- Will My Child Outgrow IBD?



The Importance of Clinical Trials - William J. Sandborn, MD, FACG

- IBD and The Importance of Clinical Trials
- Patient Success With Trials



Ulcerative Colitis -

• Ulcerative Colitis: A Guide for Patients

GastroGirl Podcast with Jacqueline Gaulin

• IBD/IBS Overlap: What Patients Need to Know

IBD Resources

- ACG Infographic on Inflammatory Bowel Disease
- National Digestive Diseases Information Clearing House Crohn's Disease Basics
- <u>National Digestive Diseases Information Clearing House Ulcerative Colitis Basics</u>
- Clinical Trials
- Crohn's and Colitis Foundation (CCF)
- IBD Resources for Teens (CCF)
- <u>CCFA Online Community</u>
- <u>Ulcerative Colitis Guidebook and Video</u>

Physician Resources

- ACG's IBD Physician Resources
- ACG's Practice Guideline for Ulcerative Colitis in Adults
- ACG's Practice Guideline for Management of Crohn's Disease in Adults