

Fact Sheet

News from the IBD Help Center

ABOUT CROHN'S DISEASE AND ULCERATIVE COLITIS

Crohn's disease and ulcerative colitis belong to a group of conditions known as inflammatory bowel diseases, or IBD. These disorders affect the gastrointestinal (GI) tract, the area of the body where digestion takes place. The diseases cause inflammation of the intestine and lead to ongoing symptoms and complications. There is no known cause or cure for IBD, but fortunately there are many effective treatments to help control it. If medications fail to control the symptoms of IBD, or if certain complications occur, surgery may be required.

- The most recent studies estimate between 1.6 and 3.1 million Americans suffer from IBD* ^{1, 2}
- Anyone can get IBD, but adolescents and young adults between the ages of 15 and 35 are the most susceptible.
 - 25 percent of the 1.6 million people with IBD will have developed their disease before age 18) ^{3, 4}
- Approximately 2-28 percent of patients have another family member with IBD, and families frequently share a similar pattern of disease. This is heavily influenced by racial/ethnic background. ⁵
- IBD often imposes a significant impact on quality of life through ongoing symptoms, reduced ability to work, social stigma, bathroom access, difficulty with physical intimacy, and a restriction in career choices. ⁶
- The unpredictable nature of these painful and debilitating digestive diseases creates a significant burden on the community and the economy: \$14.6 billion to \$31.6 billion in direct and indirect costs annually in the United States. ⁷

Symptoms & Complications

Ulcerative colitis involves the inner lining of the colon, while Crohn's disease involves all layers of the intestine and can occur in both the small intestine and colon. Symptoms range from mild to severe and even life-threatening, and include any or all of the following:

- persistent diarrhea
- abdominal pain or cramps
- rectal bleeding
- fever and weight loss

- fatigue
- joint, skin, or eye irritations
- delayed growth in children

Crohn's disease and ulcerative colitis are unpredictable illnesses. Some patients recover after a single attack or are in remission for years. Others require frequent hospitalizations and surgery. Symptoms may vary in nature, frequency, and intensity.

- Without proper treatment, symptoms may worsen considerably and complications, such as abscesses, obstruction, malnutrition, and anemia, may occur.
- Colon cancer may be a serious complication of long-term ulcerative colitis or Crohn's disease involving the colon, even in a patient who is in remission.

Treatment

Medications currently available alleviate inflammation and reduce symptoms, but do not provide a cure. Some medications used to treat Crohn's disease and ulcerative colitis have been around for years. Others are more recent breakthroughs. The most commonly prescribed medications fall into six basic categories: aminosalicylates (5-ASA); corticosteroids; immunomodulators; biologic therapies; antibiotics; and targeted synthetic small molecules. New treatments are being developed based on research of the immune system's role in the symptoms of IBD.

Surgery

Surgery is sometimes recommended when medications can no longer control symptoms, when there are intestinal obstructions, or when other complications arise.

With the benefits of new medications, the risks of surgery in patients with Crohn's disease and ulcerative colitis appear to be decreasing over time. For example, the risk of surgery for UC has decreased from about 15% before the year 2000, to about 10% currently.⁸ Some people with these conditions have the option to choose surgery, while for others, surgery is an absolute necessity due to complications of their disease.

Emotional Factors

IBD is not a psychosomatic illness -- there is no evidence to suggest that emotions play a causative role. Flare-ups of disease may occur, during times of emotional or physical stress. However, we also know that emotional factors can have an impact on how people experience their disease and symptoms, and that working with a health psychologist can result in better disease management.⁹

Diet and Nutrition

While several specialized diets may be helpful for some IBD patients, no one plan has been proven to prevent or control IBD with the exception of exclusive enteral nutrition, which is delivered in a nutrient-rich formula. There is no single diet or eating plan that will work for everyone with Crohn's disease or ulcerative colitis. Dietary recommendations must be tailored for each patient, depending on what part of the intestines is affected and what symptoms are present. There may be times when modifying a patient's diet can be helpful, particularly during a flare.

A Note about the Prevalence of IBD*

Different methods of research have produced varying estimations for the number of Americans with Crohn's disease or ulcerative colitis. For years, the Crohn's & Colitis Foundation has cited prevalence estimates from researchers from the Mayo Clinic, whose investigations of a patient population in Minnesota (1970-2010) resulted in an estimation of 1.6 million adults living with IBD in the United States, based on data obtained from medical records.³

The Centers for Disease Control and Prevention (CDC) released a much larger IBD prevalence estimate based on its 2015 National Health Interview Survey (NHIS). Through this survey, random householders were asked, "Have you ever been told by a doctor or other health professional that you had Crohn's disease or ulcerative colitis?" Affirmative answers to that question suggest an estimated 3.1 million American adults with IBD. Understanding the prevalence of IBD in our communities is important in order to identify the health and financial burdens created by Crohn's disease and ulcerative colitis, as well as inform policy and resource allocation. NHIS data indicates that the prevalence of IBD far exceeds estimates based on clinical data sources from the Minnesota study. This does not mean, however, that more targeted patient population studies are invalid: varying methodologies have different limitations and challenges. What is clear is that additional research is needed to gain greater understanding of IBD prevalence in the United States.

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