

Inflammatory Bowel Disease: Top Resources for Children, Adolescents, and Their Families

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Inflammatory bowel disease, Crohn's, ulcerative colitis, Web, information, support

It is estimated that more than 1 million people in the United States have inflammatory bowel disease (IBD), and about 10% of them are children (Bousvaros et al., 2006). Approximately 20% to 25% of all cases of IBD are diagnosed in childhood or adolescence (Gray,

Denson, Baldassano, & Hommel, 2011). The timing of the diagnosis compounded with the developmental demands of childhood and adolescence may have a profound physical and psychosocial impact on youth affected by IBD. Effective coping with this chronic and debilitating disease will require support from professionals, family, friends, and others living with IBD. This article will focus on high-quality resources on the Web and mobile health technologies that provide youth and their families with information and support for living with the challenges and uncertainties of IBD.

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ABOUT IBD

Inflammatory bowel disease (IBD) refers collectively to a group of chronic disorders: Crohn's disease (CD), ulcerative colitis (UC), or indeterminate colitis (IC). The type of IBD generally is determined by the part of the intestinal tract that is affected. Crohn's disease causes inflammation in any part of the gastrointestinal tract from the mouth to the anus and affects all layers of the intestinal wall. The inflammation associated with UC usually begins in the rectum and extends proximally in a continuous pattern; eventually, it may affect the entire colon. When a firm diagnosis of CD or UC cannot be made on the basis of standard diagnostic tests, a child with colonic disease is described as having IC (Kane, 2010).

The specific etiology of IBD is unknown. A common hypothesis for the cause of IBD is that it is the result of an unregulated intestinal immune response to environmental and bacterial triggers, probably in a host susceptible to genetic invasion (Haas-Beckert & Heyman, 2010). This response leads to the uncontrolled inflammation that causes damage to the gastrointestinal tract, resulting in symptoms.

BOX 1. General information and support for patients with inflammatory bowel disease and their families

- American College of Gastroenterology
<http://gi.org>
- American Gastroenterological Association
<http://www.gastro.org>
- Australian Crohn's and Colitis Association
<http://www.acca.net.au>
- Centers for Disease Control and Prevention
<http://www.cdc.gov/ibd>
- Crohn's & Colitis Foundation
America: <http://www.ccfa.org>
Canada: <http://www.ccfca.ca>
- ImproveCareNow (ImproveCareNow Network)
<https://improvecarenow.org/>
- National Digestive Diseases Information Clearinghouse
<http://digestive.niddk.nih.gov>
- National Health Service
<http://www.nhs.uk>
- North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
<http://www.naspgan.org>

The symptoms associated with IBD are characterized by periods of exacerbation and remission. Predominant symptoms that occur during flare-ups or exacerbations may include diarrhea, blood in the stool, and abdominal pain. Problems outside the gastrointestinal tract also may be associated with IBD. Growth failure and subsequent pubertal delay is a common manifestation of IBD in children and is related to the inflammatory process, decreased nutritional intake, malabsorption, and extensive glucocorticoid therapy (Haas-Beckert & Heyman, 2010). Extraintestinal symptoms may appear in other parts of the body and include health problems related to the eyes, bones, joints, skin, kidneys, and liver (Kane, 2010).

Children and adolescents living with IBD face difficult physical, emotional, and social challenges. Exacerbations frequently can cause affected youth to be absent from school and separated from peer and school activities. In an effort to hide their symptoms, children and adolescents with IBD may avoid telling even their closest friends about their condition, limit their food intake, or curtail use of the restroom. This attempt to hide their symptoms may lead to feelings of anxiety and depression as a result of the realization that they are different from their peers. Children with IBD appear to have more depression and anxiety than normal peers or children with other chronic illnesses (Bousvaros et al., 2006). Alterations in physical appearance and growth failure as a result of adverse effects of medications or the disease may lead to difficulties with self-esteem. In addition, periods of increased disease activity may

adversely affect family functioning (Mackner, Sisson, & Crandall, 2004).

Initial treatment usually focuses on medical therapy aimed at controlling inflammation of the gastrointestinal tract. Most persons with IBD take daily medications that may suppress the immune system, causing increased risk for infection and malignancy (Markowitz, 2008). Nutritional therapy also can be used for primary management of the disease to induce remission or as additional therapy in conjunction with medical management to improve growth and correct nutritional deficiencies. Surgery is a consideration for patients for whom medical management has failed. Surgery is curative in persons with UC but is usually palliative for patients with CD, because the disease recurs about half the time within 2 to 5 years (Jacobstein & Baldassano, 2008).

RELIABLE INFORMATION ABOUT IBD

When they are diagnosed with IBD, children and adolescents, along with their families, will want to figure out what it is and how to deal with it. No doubt, many patients and their families will turn to the Internet. An important tip to share with patients is that Google, the most popular search engine in the world, recently has introduced numerous revisions to their search algorithms to improve the searcher's chances of finding high-quality sites. Entering the general phrase *intestinal bowel disease* (or the more specific phrases *Crohn's disease* or *ulcerative colitis*) into the Google search box produces many high-quality Web sites in the top search results.

Guiding youth and parents to health information sites with domain suffixes of “.gov” (the United States government), “.edu” (a school or university), or “.org” (an organization) is a good starting point to help them find trustworthy information about IBD. Box 1 includes a list of high-quality Web sites for children, families, and health professionals who wish to know more about IBD. Disease-specific information can be retrieved on these sites by entering one of these search terms: IBD, Crohn's, or ulcerative colitis. Remind patients to pay close attention to who sponsors a Web site to determine whether there may be a particular bias in the way information is presented. Commercial or “.com” sites also may provide reliable health information but may inundate the reader with advertisements and other distracting content. Some Web sites may have two domain suffixes associated with their name—that is, a domain owner may purchase “.com” (commercial) and “.org” (organization) suffixes for their Web site to ensure that an online searcher will find his or her site no matter which suffix is entered into the address line.

The WebMD Health Professional Network owns and operates several high-quality Web sites, including eMedicine and eMedicineHealth, which provide consumers

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