A patient guide to Crohn’s disease and ulcerative colitis
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Inflammatory bowel disease (IBD) refers to chronic or long-term, relapsing (gets better and worse over time) diseases that affect the gastrointestinal (GI) tract. The GI tract is the part of the body that digests food and includes the mouth to the anus (opening of the rectum).

The two major types of IBD are Crohn’s disease and ulcerative colitis. Both conditions involve inflammation or swelling in the GI tract. Crohn's disease can affect any part of the GI tract. Ulcerative colitis affects the colon (also known as the large intestine) and rectum (the last six to 12 inches of the gastrointestinal tract). Table 1 shows a comparison of these conditions.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Crohn’s disease</th>
<th>Ulcerative colitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease location</td>
<td>May be spread through the entire GI tract</td>
<td>Limited to colon and rectum</td>
</tr>
<tr>
<td>Rectal bleeding (blood in the stool)</td>
<td>May occur</td>
<td>Common</td>
</tr>
<tr>
<td>Fever</td>
<td>Common</td>
<td>Rare</td>
</tr>
<tr>
<td>Fistula (deep ulcer that can affect surrounding tissue)</td>
<td>Common</td>
<td>Not seen</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>Common</td>
<td>May occur (lower left side of the abdomin)</td>
</tr>
<tr>
<td>Stomach mass (swelling in the belly area)</td>
<td>Common</td>
<td>Not seen</td>
</tr>
</tbody>
</table>
Who develops IBD?

In the United States as many as 1.4 million people are believed to have IBD. This number is evenly split between Crohn’s disease and ulcerative colitis. People most often develop IBD between the ages of 15 to 30, but some can develop it later in life (between ages 60 and 80 years). About 10 percent of people with Crohn’s disease are younger than 18 years of age. Both men and women can get IBD. Caucasians are more likely to develop IBD than African-Americans, Hispanics or Asians. Some Jewish people, specifically Ashkenazi Jews, are four to five times more likely to develop IBD than the rest of the population. It has been shown that persons with IBD have a genetic susceptibility for the condition.

Causes of IBD

The exact cause of IBD is not known, but it is believed to be due to a combination of factors. Factors include a person’s genes (determine hereditary traits like eye color), immune system and the environment. The immune system serves as the body’s guard against illness, but it does not always work properly. Normally, the immune system seeks out and attacks any intruder (for example, bacteria or virus) that could make a person sick. It also helps the body recover and heal after sickness. In people with IBD, the immune system does not “turn off” at the right time after attacking an intruder. When the immune system does not “turn off,” it can cause swelling in the GI tract as well as other conditions known as autoimmune disorders.

Risk factors

There are several risk factors for IBD including:

• Age (peak onset ages are 15 to 30 years)
• Family history
• Ethnicity (Ashkenazi Jews are at higher risk than other ethnicities)
• Use of an acne medication called isotretinoin (brand name Accutane®)
• Cigarette smoking (risk factor for Crohn’s disease)
• Living in urban (city) areas (risk factor for Crohn’s disease)

Diagnosing IBD

Doctors diagnose IBD based on symptoms reported by the patient, a physical examination and tests. Some tests that might be obtained are blood tests, x-rays or other body scans, and checking stool samples for bleeding or to make sure there is no infection. The doctor will also need to look inside the GI tract with one or more tests. Some of these tests include:

• Colonoscopy – a thin, flexible tube with a camera is used to view the entire colon
• Flexible sigmoidoscopy – a thin, flexible tube is used to view the end of the colon
• Upper endoscopy – a flexible tube with a camera is used to view the upper portion of the digestive system, i.e., stomach and small intestine
Understanding your diagnosis of Crohn's disease or ulcerative colitis can help you better manage your health. Although Crohn's disease and ulcerative colitis are long-term conditions, there are a number of available treatment options that can improve the symptoms. Beginning treatment soon after being diagnosed can help to maintain your lifestyle and improve your overall health. This booklet will provide you with information about Crohn's disease and ulcerative colitis, what to expect after being diagnosed and how to manage the symptoms to live a full and active life.

**Clinical findings and disease course**

Crohn's disease is a long-term condition that gets better and worse over time. There is no cure, but symptoms can usually be controlled with medication. The condition is considered active when symptoms are present. This is also called a flare. Remission is a time when no symptoms are present. Symptoms of Crohn's disease include:

- Diarrhea
- Reduced appetite and weight loss
- Abdominal pain/cramping
- Blood in the stool (more common with ulcerative colitis)

When Crohn's disease is more severe, it can affect the whole body as follows:

- Arthritis (joint swelling)
- Feeling tired
- Fever
- Skin disorders
- Swelling of the eyes

**Crohn’s disease**

**Who develops Crohn’s disease?**

About 20 to 40 people per 100,000 people in the United States have Crohn’s disease. Cases of Crohn’s disease have been dramatically increasing over the last 30 to 40 years. Experts are not sure why the condition is becoming more common.

**Classification of Crohn’s disease**

Crohn's disease can be mild or very severe. The classifications used to describe Crohn's disease are listed in Table 2.

<table>
<thead>
<tr>
<th>Classifications</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptomatic remission</td>
<td>No current symptoms or complications</td>
</tr>
<tr>
<td>Mild–moderate</td>
<td>Able to walk and get around and eat food without problems</td>
</tr>
<tr>
<td>Moderate–severe</td>
<td>Treatment for mild–moderate disease did not work OR symptoms of fever, weight loss, abdominal pain, nausea (upset stomach), vomiting or anemia (low red blood cell count)</td>
</tr>
<tr>
<td>Severe/fulminant (occurring suddenly with great severity)</td>
<td>Symptoms continue even with medication therapy OR high fevers, continued vomiting, obstruction (blockage in the intestine) or wasting syndrome (severe weight loss and weakness) are present</td>
</tr>
</tbody>
</table>
Ulcerative colitis

Who develops ulcerative colitis?

About 80 to 120 people per 100,000 people in the United States have ulcerative colitis. The number of people with ulcerative colitis has been similar over the years, unlike Crohn’s disease, which, as stated earlier, is becoming more common. Experts are not sure why Crohn’s disease is becoming more common.

Classification of ulcerative colitis

Ulcerative colitis can be mild or very severe. The classifications used to describe ulcerative colitis are listed in Table 3.

Clinical findings and disease course

Ulcerative colitis is a long-term condition that gets better and worse over time. There is no cure, but symptoms can usually be controlled with medication. Surgery is reserved for difficult to treat cases. Symptoms are based on the part of the body that is affected but can include:

- Bloody diarrhea
- Rectal pain/bleeding
- Abdominal pain/cramping
- Urgent feeling to have a bowel movement
- Weight loss

Table 3: Classifications of ulcerative colitis

<table>
<thead>
<tr>
<th>Classifications</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>Less than four stools per day (with or without blood); normal erythrocyte sedimentation rate (ESR)—a test that indirectly measures how much inflammation is in the body; no other symptoms</td>
</tr>
<tr>
<td>Moderate</td>
<td>More than four stools per day; few other symptoms</td>
</tr>
<tr>
<td>Severe</td>
<td>More than six bloody stools per day; fever, fast heart beat, anemia (low red blood cells) or a high ESR</td>
</tr>
<tr>
<td>Fulminant (occurring suddenly with great severity)</td>
<td>More than 10 stools per day with bleeding that doesn’t stop; stomach tenderness, puffing out of the stomach and need for blood transfusion</td>
</tr>
</tbody>
</table>
Living with Crohn’s disease and ulcerative colitis

Although there is no cure for Crohn’s disease or ulcerative colitis, there are many ways to treat the symptoms of these conditions. A doctor who specializes in GI disorders, known as a gastroenterologist, may treat you. It is important that you work with your doctor and pharmacist to find the best treatment approach for you. The main goals of therapy for Crohn’s disease and ulcerative colitis are to:

• Decrease swelling in the GI tract
• Improve quality of life
• Reduce complications (see below)
• Reduce the need for steroids (medications used for IBD)
• Stop symptoms (remission)

Treatment usually works to control symptoms, but flares (symptoms return) can happen. The reasons why flares may occur include:

• Not taking medication or taking the wrong amount
• Eating certain foods
• Smoking (for patients with Crohn’s disease)
• Stress
• Use of certain medications like nonsteroidal antiinflammatory drugs (NSAIDs, for example ibuprofen [Motrin®, Advil®] or naproxen [Aleve®]) or antibiotics

Crohn’s disease and ulcerative colitis can cause complications. Crohn’s disease may cause:

• Anemia (low red blood cell counts)
• Arthritis (swollen joints)
• Eye complications related to swelling
• Fistula (deep hole in the intestine that can pass into surrounding tissue)
• Lack of proper nutrition (can lead to growth problems in children)
• Obstruction (blockage in the intestine, which can prevent food from moving through)
• Ulcers in the digestive tract
• Liver disease
• Red bumps or ulcers on the skin

Ulcerative colitis may cause:

• Ankylosing spondylitis (swollen joints in the spine)
• Arthritis (swollen joints)
• Colon cancer
• Eye complications related to swelling
• Liver disease
• Red bumps or ulcers on the skin
• Toxic megacolon (ballooning and loss of muscle in the colon)

Medication therapies

Medication therapies, along with lifestyle changes, can help you improve your overall health. Not all treatments work for everyone, so it is important that you talk with your doctor or pharmacist about what works best for you now and as your needs change over time. More information about medication therapies is provided in the companion booklet, Understanding your Crohn’s disease and ulcerative colitis medications.
Lifestyle changes

There are ways to cope with IBD symptoms in addition to taking medications. Plan ahead for public outings by locating restrooms in advance. Bring along extra underclothing and toilet paper. Always discuss travel with your doctor and make sure to bring enough medication to last for the trip.

Your doctor may ask you to keep track of your symptoms in a diary. It may be helpful to write down the number of bowel movements you are having each day, as well as how soft or hard the stool is. Your doctor may also want you to keep track of changes in your weight and any other symptoms. You can use a notebook to create your diary or search online for electronic versions.

Getting regular physical activity, eating right and managing stress can help you feel better each day. These changes can also help improve your IBD.

Smoking is a risk factor for the development of Crohn’s disease. Smoking can also make Crohn’s disease more severe. If you have Crohn’s disease and smoke, you should quit. Talk to your doctor or pharmacist about ways to stop smoking.

Physical activity

While regular exercise can help maintain a healthy weight to reduce the risk of heart disease. It can also minimize joint stress, which is beneficial if joint problems are a complication of your IBD. Talk to your doctor or physical therapist about different types of exercise and what might be appropriate for you:

• Aerobic, including walking or swimming
• Strengthening, such as weight training
• Stretching and range-of-motion, like gentle yoga or tai chi

Maintaining emotional health

You can also improve your physical health by improving your emotional health. High levels of stress might increase your tendency to experience flares and might make it more difficult to deal with the challenges of living with Crohn’s disease/ulcerative colitis.

You can take steps to understand and control your stress:

• Develop positive ways to cope, like making time for hobbies you enjoy or relaxing in a quiet space each day
• Spend some time to find out what stresses you by keeping a journal or diary
• Try to avoid things that add to your stress

Sometimes, you might find yourself feeling frustrated or sad about your Crohn’s disease/ulcerative colitis. It’s normal to feel this way, especially when first diagnosed, in the early stages of the disease or during a flare (when you are having symptoms). It can help to seek support from friends and family or take extra time to do things that make you happy. You might want to find a support group or online message board for people with Crohn’s disease or ulcerative colitis.
The mind and the body are closely related. You may feel sad or get depressed because you have IBD. It’s also important to know that symptoms of depression may include some or all of the following:

- Being tired or lacking energy
- Eating too much or too little
- Feeling restless or irritable
- Feeling sad, empty or anxious most of the time
- Feeling worthless, helpless or guilty
- Having difficulty concentrating or making decisions
- Losing interest or pleasure in activities that you used to enjoy
- Sleeping too much or too little
- Thinking about death or suicide

Children and teenagers who are depressed may have different symptoms than adults. Symptoms of depression in children and teenagers may include some or all of the following:

- Frequent sadness, tearfulness, crying
- Decreased interest in activities
- Hopelessness
- Low energy; constant boredom
- Social isolation
- Low self esteem
- Extreme sensitivity to failure
- Increased anger
- Frequent complaints of headaches or stomachaches
- Poor performance in school or numerous absences
- Poor concentration
- A major change in eating/sleeping patterns
- Talking about running away from home

If you or your child have thoughts of suicide, you should call 9-1-1 or your local emergency services number. If you don’t want to do that, contact your doctor, mental health professional, crisis center or hotline immediately.

If you think you or your child may be depressed, talk with your doctor. Your doctor may recommend counseling, medications or a combination of both.

**Protecting your bones**

Since steroids may contribute to osteoporosis, you may want to keep track of the health of your bones if you are taking steroids for IBD. Although osteoporosis is more commonly known as a disease affecting women, it may affect both men and women who take steroids. Your doctor may want you to take a bone density test. This test looks at the strength of your bones and can assess your risk of breaking a bone. There are several steps you can take to help prevent osteoporosis, including the following:

- Get enough calcium and vitamin D in your diet. Talk to your doctor about the right amount and how best to reach that level.
- Do gentle, weight-bearing exercise, like walking, as recommended by your doctor.
- Do not smoke cigarettes.
- Drink alcohol only in limited amounts.

If your child is treated with steroids long-term, there is a potential for a reduction in growth and weak bones. Children are sometimes treated with steroids every other day to minimize the effects if IBD, but long-term use of steroids can affect the strength of your child’s bones. Your child’s doctor can give you more information about protecting your child’s bones.

**Proper nutrition**

Poor nutrition is very common in patients with IBD. This is especially true for Crohn’s disease when the intestines are less able to digest and absorb nutrients from food. Your doctor may ask you to meet with a dietitian to get advice on proper nutrition. The most important thing is to eat a well-balanced, healthy diet and to drink enough fluids. There is no list of foods to avoid, but certain foods may bother some people. For example, people with IBD who are lactose-intolerant may need to avoid milk and dairy products. You should consider keeping a food diary to track what you eat and any symptoms you may have. A diary may
help pinpoint which foods, if any, are bothering you. A food diary also allows the doctor or dietitian to see if you are getting enough nutrients from your diet. You can use a notebook to create your diary or search online for electronic versions.

If you have Crohn’s disease and have a narrowing of your small intestine, a low-fiber, low-residue diet may be helpful. A low-residue diet means avoiding foods that leave a lot of undigested material to pass through the intestines. This kind of diet can reduce the number and size of your stools. Low-residue diets are usually only needed for a short period of time until your condition is better controlled. Examples of foods that can be eaten as well as those that should be avoided in a low-residue diet are listed in Table 4.

During flares, eating smaller, more frequent meals is suggested. Five small meals (fist-sized portions) every three or four hours is better than three larger meals. Reducing the amount of greasy or fatty foods, such as fried foods, may also help during this time. Greasy foods can cause diarrhea and gas. Talk with your doctor or dietitian about how to get proper nutrition. This is especially important for children with IBD. Children need proper nutrition to grow appropriately.

### Surgery
You may need surgery for IBD if medications and other treatments are not effective in controlling symptoms. About two-thirds to three-quarters of people with Crohn’s disease will need surgery at some point in their life. About one-quarter to one-third of people with ulcerative colitis may need surgery at some point. Some of the common surgical procedures for Crohn’s disease and ulcerative colitis are listed in Table 5.

#### Table 4: Low-residue diet*

<table>
<thead>
<tr>
<th>Foods that can be eaten</th>
<th>Foods to avoid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refined breads, cereals, crackers, etc. with 0 or &lt;1 gram of dietary fiber per serving</td>
<td>Popcorn, seeds, nuts, whole grains</td>
</tr>
<tr>
<td>White rice</td>
<td>Berries, dried fruits</td>
</tr>
<tr>
<td>Vegetable juice without seeds or pulp</td>
<td>Broccoli, cauliflower, Brussels sprouts, cabbage</td>
</tr>
<tr>
<td>Fruit juice without pulp</td>
<td>Peanut butter</td>
</tr>
<tr>
<td>Clear carbonated beverages, sports drinks</td>
<td>Marmalade</td>
</tr>
<tr>
<td>Dairy products (limit 2 cups per day), for example milk, yogurt, pudding, cream-based soups</td>
<td>Tough meats or meats with gristle</td>
</tr>
<tr>
<td>Broth-based soups</td>
<td></td>
</tr>
<tr>
<td>Jelly</td>
<td></td>
</tr>
<tr>
<td>Well-cooked, tender, meat, fish, chicken and eggs</td>
<td></td>
</tr>
<tr>
<td>Canned fruit cocktail, honeydew melon, peaches without skin, watermelon</td>
<td></td>
</tr>
</tbody>
</table>

*This is not a comprehensive list. Please see your dietitian or nutritionist for further information.
**IBD and pregnancy**

It does not seem that IBD affects a woman's chances of becoming pregnant. Also, pregnancy does not seem to affect the symptoms of IBD. Becoming pregnant while IBD is in remission is better for the mother and the baby. Active disease during pregnancy has been linked to delivering the baby early.

Women who have Crohn's disease or ulcerative colitis and are pregnant or plan to be pregnant soon, should talk to their doctor or pharmacist about their medications. Some medications can also affect fertility for both men and women. For women, who plan to breastfeed, it is important to ask your doctor or pharmacist which medications are safe to take before you begin breastfeeding your baby.

**Ongoing care**

You should continue to see your doctor regularly to see how well your medication and other therapies are working. Regular visits will also help your doctor adjust treatment if necessary. To monitor your progress, your doctor will likely ask you questions about the symptoms of your disease and may perform lab tests. Your doctor will also monitor any side effects you might experience from medications and make changes, if needed.

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Crohn's disease</strong></td>
<td></td>
</tr>
<tr>
<td>Fistula repair</td>
<td>Removing the damaged part of the bowel and fixing connections between different parts of the GI tract that shouldn't be there</td>
</tr>
<tr>
<td>Remove obstruction</td>
<td>Unblocking the intestine</td>
</tr>
<tr>
<td>Drain an abscess</td>
<td>Removing fluid from an abscess (collection of puss) with a needle</td>
</tr>
<tr>
<td>Strictureplasty</td>
<td>Widening the part of the intestine that has become too narrow</td>
</tr>
<tr>
<td>Resection</td>
<td>Removing the diseased portion of the bowel</td>
</tr>
<tr>
<td>Colectomy/proctocolectomy</td>
<td>Removing all or part of the colon; proctocolectomy involves removal of colon and rectum</td>
</tr>
<tr>
<td><strong>Ulcerative colitis</strong></td>
<td></td>
</tr>
<tr>
<td>Total proctocolectomy with ileostomy</td>
<td>Removing the colon and rectum and creating an ileostomy (an opening through the stomach wall that allows waste to empty into an attached pouch)</td>
</tr>
<tr>
<td>Restorative proctocolectomy/ileal pouch anal anastomosis (IPAA)</td>
<td>A two-stage operation that does not require a long-term ileostomy</td>
</tr>
</tbody>
</table>
To learn more

The more informed you are, the better you can manage your health. Our specialty pharmacy care team provides personalized, supportive and dependable care to help you achieve the best results from your prescribed therapy.

Sources

The following sources were used in the development of this booklet and the companion piece, *Understanding your Crohn’s disease and ulcerative colitis medications.*


Resources

American College of Gastroenterology (AGA)
www.acg.gi.org/patients/ 301-263-9000

The American College of Gastroenterology includes close to 12,000 digestive health specialists. The group’s website contains information for patients about GI disease, colonoscopies, and answers to frequently asked questions. You can also use the website to find a gastroenterologist, a doctor who specializes in treating IBD and other conditions. The website contains links to other patient support and education resources. Information is also available in Spanish.

American Society of Colon & Rectal Surgeons (ASCRS)
www.fascrs.org/patients/ 847-290-9184

The American Society of Colon & Rectal Surgeons includes over 2,600 members who specialize in treating patients with conditions that affect the colon, rectum and anus. The group’s patient website provides information about colon and rectal surgeons, medical conditions and how to find a surgeon.
Crohn’s & Colitis Foundation of America (CCFA)
www.ccfa.org/
800-932-2423
The Crohn’s & Colitis Foundation of America is a non-profit, volunteer-driven organization that is devoted to finding a cure for Crohn’s disease and ulcerative colitis. The foundation sponsors research on these conditions. Their website contains several pages of information designed for patients. Topics include treatment, nutrition and diet and surgery options. Brochures, webcasts, information on clinical trials and links to other organizations are also provided. You can use the website to find a doctor. Additional information, including a site for teenagers, is available on their website named “I’llBDetermined” (www.ibdetermined.org/CCFAResources/).

MedlinePlus
www.nlm.nih.gov/medlineplus/ulcerativecolitis.html (ulcerative colitis)
MedlinePlus is a service of the United States National Library of Medicine and the National Institutes of Health (NIH). The purpose of the website is to provide patients with information about various medical conditions. Information includes nutrition, alternative therapies, disease management and background. Information specific to women, children, and teenagers is available. Tutorials link to other NIH websites, including the National Digestive Diseases Information Clearinghouse. Information is also available in Spanish.

Mayo Clinic
www.mayoclinic.com/
480-301-8000
The Mayo Clinic is a healthcare organization where people can get treatment for a variety of conditions. The organization’s website contains patient information on many conditions, including Crohn’s disease and ulcerative colitis. Information about diet and nutrition is also available. The best way to find the information is to search the Clinic’s website or use a search engine and type in the condition and Mayo Clinic. The website also allows you to search for a doctor at Mayo Clinic.