GI Kids
Help & Hope for Children with Digestive Disorders
www.GIKids.org

Crohn's Disease

What is Crohn's disease?

Crohn's disease is one of the most common forms of inflammatory bowel disease (IBD). It is associated with inflammation of the digestive tract. The digestive tract runs from the mouth to the anus and includes the stomach and both small and large intestines. Inflammation can irritate deeper layers of digestive tissue as well as the lining.

What are the different types of Crohn's disease?

The type of Crohn's disease depends on the affected part of the digestive tract. The disease can also be classified by its severity. The most common areas that are involved are the terminal ileum (last part of the small intestine) and the colon (large intestine).

What causes Crohn's disease?

Both genetic and environmental factors likely interact to cause Crohn's disease. More than 200 different genes may affect the risk of Crohn's disease. While limited information exists about the environmental causes of Crohn's disease, living in a northern country (such as the United States, Canada, or northern Europe) and use of antibiotics in early life may increase risk of the disease.

How common is Crohn's disease?

Crohn's disease is common, and it affects people of all ages. In the United States, more than 1 million children and adults have either Crohn's disease or ulcerative colitis. Some of the important risk factors for developing Crohn's disease are:

- Family history of IBD
- Previous surgery to remove the appendix
- Maternal smoking
- Exposure to antibiotics early in life

Who develops Crohn's disease?

Your child may have mild watery diarrhea that lasts only a few days and resolves on its own. In some children, the symptoms may persist for months with associated blood.

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

Your child may present with few or all of these symptoms:

- Abdominal pain - the pain may be in the lower right part of the abdomen, around the belly button or above the belly button. This pain may be persistent, severe, and could possibly wake your child from sleep.

- Diarrhea - passage of watery stool or frequent stool that is different from your child's normal pattern. It could be mild to severe and may frequently wake your child from sleep.
- Constipation - in some cases, your child may have constipation, although this is usually in combination with other symptoms.
- Blood in the stool
- Weight loss
- Poor growth (not gaining height as quickly as expected or similarly to other children)
- Nausea/vomiting
- Perianal disease (cracks or painful bumps in the anal area)
- Unexplained fevers

Other symptoms are referred to as extra-intestinal manifestations. These symptoms occur outside the digestive tract, including:

- **Skin:** Unusual skin rashes (may be called erythema nodosum or pyoderma gangrenosum)
- **Joints:** Pain and swelling of joints; ankylosing spondylitis (lower back pain, spine inflammation)
- **Eyes:** Inflammation of the white part or colored part (iris) of the eye (called uveitis, episcleritis, or iritis)
- **Mouth:** Oral sores (canker sores), which may range in severity from painless to severe and are usually recurrent
- **Kidneys:** Kidney stones; rarely, blood in the urine; kidney inflammation (called interstitial nephritis) can sometimes develop with Crohn's disease or due to medication used to treat Crohn's disease
- **Bone:** reduced bone mineral density and weak bones (called osteopenia), which may result from malnutrition, inadequate caloric intake or malabsorption, vitamin D deficiency, or excessive corticosteroid intake after Crohn's disease diagnosis and which may result in increased risk of bone fracture
- **Blood:** anemia, which may result from iron, folate, or vitamin B-12 deficiency or may be caused by medications used to treat Crohn's disease, such as 6-mercaptopurine or azathioprine
- **Vessels:** increased risk of blood clotting may occur, especially in children with active disease.
- **Liver:** inflammation of the liver may occur due to some rare associated conditions (autoimmune hepatitis, primary sclerosing cholangitis), or due to medications
- **Pancreas:** inflammation of the pancreas (called pancreatitis), which may develop as a reaction to drug therapy (6-mercaptopurine and sulfasalazine) or from unknown causes

Your primary care physician will perform an initial evaluation if you are concerned that you or your child has Crohn's disease. Ask your doctor for referral to a pediatric gastroenterologist if your child has blood in the stool, persistent diarrhea, persistent abdominal pain, weight loss, poor growth, or pain/swelling around the anus.

How is Crohn's disease diagnosed?

Diagnosis is made through history, physical examination, and testing. The following tests are used to diagnose Crohn's disease in children:

- **Blood:** Your doctor may collect blood to test for inflammatory markers, such as erythrocyte (red blood cell) sedimentation rates or C-reactive protein, as well as a complete blood count to test for high platelet levels (called thrombocytosis), low red blood cells (called anemia), or comprehensive metabolic panel [hypoalbuminemia (low protein) or abnormal electrolytes.
- **Stool:** Stool culture may be done to rule out bacterial infection in the gut. Markers of inflammation that can be identified in the stool (calprotectin or lactoferrin) may be tested.
- **Imaging:** The following imaging tests may be used to diagnose Crohn's disease:
  - Contrast studies, upper GI series with small bowel follow-through
  - Abdominal computed tomography (CT) scan
  - Magnetic resonance enterography (MRE) - this may be performed instead of a CT scan because CT scans expose the patient to radiation
  - Ultrasound - while not commonly used to diagnose Crohn's disease, it can used to monitor disease activity and response to treatment
  - Endoscopy and colonoscopy: These are the main tests to confirm Crohn's disease. Esophagogastroduodenoscopy (EGD) uses an endoscope to inspect the digestive tract, including the esophagus, stomach, and part of the intestines. Colonoscopy uses an endoscope, or tube with a camera, to inspect the colon and small intestine. Your child will need a clean-out (taking laxatives to empty the digestive tract of stool) before colonoscopy.

What is the treatment for Crohn's disease?

Your doctor will discuss different therapies for Crohn's disease depending on the severity. Your doctor may mention therapies for induction of remission (to make the symptoms disappear) or maintenance of remission (to prevent the symptoms from returning). Crohn's disease treatment can include a combination of:

- Medication
- Diet and nutrition
- Complementary therapy
- Surgery

MEDICATION

Therapy for induction of remission for moderate to severe Crohn's disease includes the following medications. Each medication has its own risks and benefits. Your gastroenterologist should review both the effectiveness and potential side effects in detail with you and your child.

Corticosteroids: prednisone, prednisolone, methylprednisolone, budesonide. These medications are used for a short time (a few weeks to a few months) to control symptoms. These medications are never stopped abruptly. Your doctor will tell you how to gradually reduce the dose to stop treatment. Because the body breaks down and processes these medications differently, some medications have significant side effects while others do not.

Aminosalicylates: sulfasalazine, mesalamine (brand names: Pentasa®, Asacol®, Lialda®, Apriso®), olsalazine, balsalazide These are among the safest medications used to treat mild Crohn's disease. These medications also have their own side effects but can be used long-term as maintenance treatment. They are usually ineffective for moderate to severe Crohn's disease.

Antibiotics: metronidazole, ciprofloxacin (brand name: Cipro®). Antibiotics are often used to treat infectious complications of Crohn's disease, such as abscesses. These medications have anti-inflammatory properties and can be used to treat active Crohn's disease. They are used for short periods and not for maintenance.

Immunomodulators: azathioprine (AZA) and 6-mercaptopurine (6MP). These medications are primarily used as maintenance treatment in Crohn's disease. They are used with other medications, such as biologics or aminosalicylates. They may also be used when your doctor is trying to discontinue corticosteroid use. These medications typically take 3–6 months to be effective.

Methotrexate is another immunomodulatory medicine used as a maintenance treatment for Crohn's disease. This medicine typically takes 4 weeks to be effective.

Anti-tumor necrosis factor (TNF) agents or TNF inhibitors: infliximab (brand name: Remicade®), adalimumab (brand name: Humira®), golimumab (brand name: Simponi®), and certolizumab pegol (brand name: Cimzia®). Anti-TNF agents are usually used in patients with moderate to severe IBD and are among the most effective treatments.

Anti-integrin agents: vedolizumab (brand name: Entyvio®), natalizumab (brand name: Tysabri®). Anti-integrin agents are used in patients with Crohn's disease who fail to respond to corticosteroids, immunomodulators, and anti-TNF agents. These medicines frequently take a longer time (months) to have an effect. Your doctor may sometimes add other medications during this waiting period.

Anti-interleukin agents: ustekinumab (brand name: Stelara®). Anti-interleukin agents are usually used in Crohn's disease patients who do not respond to corticosteroids, immunomodulators, and anti-TNF agents.

Talk to your pediatric gastroenterologist about the therapy that is right for your child.

DIET AND NUTRITION

Nutritional therapy may be suggested for your child as a primary treatment without medicines. It is very important if your child is suffering from malnutrition or poor weight gain. Nutrition therapy can also be used for induction and maintenance of remission.

Nutritional therapies can be given in the form of:

- Total parenteral nutrition: Nutrition given through the vein (intravenously) and bowel rest
- Enteral nutrition: Nutrition give either orally or through a naso-gastric (NG) tube (a dietitian will discuss different nutritional enteral formulas)
- Placement of gastrostomy tube: This may be indicated for long-term enteral therapy for those who do not want to use an NG tube

If nutritional therapy is suggested, your child's doctor will discuss these options with you.

ALTERNATIVE/COMPLEMENTARY THERAPY

Alternative therapy is treatment for Crohn's disease that is not traditional medical therapy. Complementary therapies are used in combination with traditional medicine.

Some research has been done on complementary and alternative therapies in people with Crohn's disease. However, there is not enough research to determine if many of these

therapies work. Discuss these options with your child's gastroenterologist before starting any complimentary/ alternative therapies.

Herbal supplements: Echinacea, St. John's Wort, Ginkgo, Garlic, Saw Palmetto. These are dietary supplements and are not recommended for active Crohn's disease. Research has not proven if many plants can be used as medicines, especially not to treat Crohn's disease.

Probiotics: *Saccharomyces boulardii,* VSL#3, *Lactobacillus rhamnosus* GG. These supplements contain good bacteria that live in the human body. They work with the body to create an overall healthy environment. While commonly used by patients, and generally safe, there is no compelling evidence that they are effective.

Fish oil contains omega-3 fatty acids, which are essential to the human diet, along with omega-6 and omega-9. Omega-3 fatty acids may help with inflammation. Omega-3 fatty acids come from foods because our bodies do not produce these fatty acids. They can be obtained through foods such as fatty fish (salmon, herring, and mackerel) and some green vegetables.

Discuss with your doctor before starting any alternative/ complementary therapy.

SURGERY

Surgery may be recommended for complications of Crohn's disease, or to remove a damaged part of the intestines.

Surgery may cause the disease symptoms to resolve (remission), although disease often comes back later (recurrence). After surgery, your child may need to take preventative medicines, such as infliximab (brand name: Remicade®).

For more information, go to https://www.gikids.org and watch Treatment Options for Pediatric Crohn's: A Guide for Patients and Families-Video.

What are the complications of Crohn's disease?

- Intestinal blockage and/or tearing
- Drug allergies and/or resistance
- Perianal disease
- Bleeding
- Formation of an abnormal connection between organs (fistula)
- Abnormal narrowing of a body passage (stricture)
- Abscess within the abdomen and/or around the rectum (perirectal)
- Growth failure

What are possible outcomes of Crohn's disease?

Although the disease may disappear (remission), it may come back later (recurrence). Often medication needs to be continued to maintain remission and keep a patient healthy. In many patients, remission can be achieved without steroids, but this usually requires the use of biologics (anti-TNF, vedolizumab, ustekinumab).

Some children may have more persistent inflammation, which requires intermittent to ongoing steroid treatment. Such cases require careful clinical evaluation and management to prevent complications.

Where can I find support for my child and family?

In addition to online resources, there are many community support groups. Ask your doctor or nurse about local community support groups, such as the Power of 2 Program. Additional resources include the Crohn's and Colitis Foundation, IBD Support Foundation, NASPGHAN Foundation, and ImproveCareNow.

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➡ Locate a Pediatric Gastroenterologist

IMPORTANT REMINDER: *This information from the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) is intended only to provide general educational information as a definitive basis for diagnosis or treatment in any particular case. It is very important that you consult your doctor about your specific condition.*

NASPGHAN
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