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Inflammatory Bowel Disease (IBD)

Inflammatory Bowel Disease (IBD) is a chronic inflammatory disorder of the intestines that does not have an identifiable cause (such as infection). IBD is thought to arise from the abnormally active immune system that reacts to food, bacteria and other contents of the gastrointestinal (GI) tract. This abnormal immune reaction causes persistent inflammation and damage to the bowels presenting as abdominal pain, diarrhea often with blood, weight loss and poor growth. There are over 3 million Americans affected by IBD and about 1/4th have onset in children.

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What are the types of inflammatory bowel disease?

There are 2 major types of inflammatory bowel disease: Crohn's disease (CD (<https://gikids.org/digestive-topics/crohns-disease/>)) and ulcerative colitis (UC (<https://gikids.org/ulcerative-colitis/>)). Ulcerative colitis causes inflammation that is largely limited to the large intestine (the colon). In contrast, Crohn's disease can involve any part of the GI tract including the mouth, esophagus, stomach, small intestine and colon. Most patients with CD however, have disease that affects the last part of the small intestine (terminal ileum) and the large

intestine. Some patients may be diagnosed with indeterminate colitis. This means it has features that can be consistent with either CD or UC and has not declared itself. Crohn's disease and ulcerative colitis are discussed in more detail in separate sections in GI kids.

Clinicians also utilize the term very early onset inflammatory bowel disease (VEOIBD) to describe disease that occurs in children under the age of 6 years. Many of these VEOIBD patients have disease similar to the IBD seen in older children and adults, while others have more unique features. This is a unique subset of patients that require more evaluation of other possible causes.

Some basic facts on inflammatory bowel disease

- The exact cause of IBD is unknown, but both individual genetic and environmental factors may be involved.
- Patients with IBD can also have inflammation in other parts of their body, including the skin, joints, eyes, or liver.
- Inflammatory bowel disease should not be confused with irritable bowel syndrome (IBS). IBD patients are usually sicker, with diarrhea, abdominal pain, rectal bleeding, and weight loss. Colonoscopy usually will show evidence of inflammation that is confirmed on biopsy. In contrast IBS may cause abdominal pain and diarrhea, but usually the symptoms are milder. In IBS, colonoscopy and biopsies are normal.
- Patients with IBD require close follow-up by a pediatric gastroenterologist or IBD specialist. Treatment of IBD involves a combination of medical and nutritional therapies. In some patients, surgery may be necessary.
- Children with IBD often lead a normal life and able to achieve their life goals like other children

Symptoms & Diagnosis of IBD

Does My Child have IBD?

Symptoms of IBD can appear at any age. The two most common forms of IBD are ulcerative colitis (UC) (<https://gikids.org/ulcerative-colitis/>) and Crohn's disease (CD) (<https://gikids.org/digestive-topics/crohns-disease/>). The symptoms of these two diseases can be very similar. If your child has IBD symptoms, contact your pediatrician for an evaluation.

Pediatric IBD symptoms checklist:

- Diarrhea, sometimes with blood and mucus
- Belly pain
- Loss of appetite
- Weight loss
- Unexplained fever and tiredness
- Poor growth
- Mouth sores

Diagnosing Pediatric IBD:

If your physician suspects your child has IBD, he or she will likely run several diagnostic tests, including:

- Blood tests
- Poop tests
- X-rays and other radiology tests
- Endoscopy of the upper and lower GI tract

IBD could run in families, your physician may inquire about your family's medical history. If your child is experiencing IBD symptoms discuss them with your family doctor or find a pediatric gastroenterologist

(http://members.naspghan.org/NASPGHANMembers/Find_a_Pediatric.aspx) near you.

Treatment & Management of IBD in Children

IBD may be a progressive disease (meaning it can get worse over time), early diagnosis and treatment have a potential to prevent damage and impact the long-term well-being of your child.

The management of IBD differs in each patient and depends on several factors including the diagnosis, severity of disease symptoms, extent of the disease (how much of the bowel is affected), age of the child, and other underlying medical problems.

General goals of IBD management include-

- Get rid of symptoms and prevent recurrence of symptoms
- Improve quality of life
- Promote and enable normal, unrestricted activity
- Promote growth and optimal nutrition
- Avoid hospitalizations, emergency room visits and absences from school
- Limit usage of systemic (oral and IV) corticosteroids
- Prevent long-term complications of disease and treatment related side effects

From a medical view, the goal of treating IBD is mucosal healing or deep remission. This means the child feels well **and** does not show signs of inflammation. Mucosal healing is defined as not seeing disease activity upon colonoscopy or other imaging methods like MRI or CT scans. Your GI doctor also runs blood tests and stool tests periodically to make sure inflammation is indeed under good control. It is shown that mucosal healing not only prevents frequent flares, it also prevents long-term complications like narrowing (stricture) of the intestines, hospitalizations and even colon and intestinal cancers.

Treatment involves several different approaches and personalized to each patient and may include individual or combination of each of the following approaches.

- Diet and Nutrition
- Medical and surgical interventions
- Complementary/alternative medicine (CAM)

Consult with your child's health care team to determine the best treatment for his or her specific condition.

Medical Treatment for IBD

Corticosteroids

This group of medications is often referred to as steroids and are strong anti-inflammatory agents used to treat moderate to severe IBD. They are primarily used for induction (meaning to get the inflammation under control quickly) thus helping with resolution of symptoms. They are usually used short-term (a few weeks to a few months) and need to be weaned (decreased gradually or tapered) when stopping. When children take steroids, their bodies stop making cortisol, a hormone naturally made in the body by adrenal glands. The purpose of the wean is to let body take over the production when we stop the corticosteroid medications.

Corticosteroids are available in oral, rectal, and intravenous (directly given in to vein) forms. The commonly used forms of corticosteroids in IBD include-

- Prednisone or prednisolone
- Methylprednisolone
- Hydrocortisone
- Budesonide (brand names: Entocort® EC, Uceris™)

Budesonide is part of a new class of corticosteroids called non-systemic steroids because they target the intestine rather than the whole body. By doing so, they cause fewer side effects. Budesonide capsules are designed to slow the release of budesonide until the drug reaches the ileum and right side of the colon (Entocort EC) or in the entire colon (Uceris)

Corticosteroids are associated with various side effects, which depend on the type of corticosteroid, dose, and length of treatment. They are only recommended for short-term to achieve remission. Long-term and frequent use of corticosteroids is not recommended because of their undesirable side effects.

Some common side effects of corticosteroids include-

- Increased appetite and weight gain
- Swelling of face

- Acne and facial hair
- Mood changes and sleep disturbances
- Hyperactivity
- Increased risk of infections

Some long-term and rare side effects when systemic corticosteroids are used frequently and for prolonged periods include-

- Growth failure
- Weak bones (osteopenia)
- Avascular necrosis of the femur (leads to change in gait and hip pain)
- Diabetes mellitus (poor sugar control)

Aminosalicylates

Sulfasalazine, Olsalazine, Mesalamine, Balsalazide

Aminosalicylates or 5ASAs are among the safest medications used to treat IBD but are generally effective only in mild to moderate cases of ulcerative colitis. They work directly on the lining of the bowel to decrease inflammation. There are typically given as oral (liquid, pills or capsules) and rectal medications (suppositories and enemas).

The most common side effects with 5-ASAs include headache, diarrhea, bloating and nausea. Rarely they are associated with allergic reactions presenting most commonly as skin rash.

Antibiotics

Metronidazole, Ciprofloxacin (Cipro®)

Antibiotics are often used to treat infectious complications of inflammatory bowel disease; such as abscesses in the abdomen or around the anus (perianal). They also may be used to treat mildly active Crohn's Disease and are sometimes utilized to treat mild flares of ulcerative colitis.

Immunomodulators

Immunomodulators are medicines that decrease the normal immune system response. These are typically used to treat moderate to severe Crohn's disease and ulcerative colitis. They are sometimes used in combination with biologics (see below). They are safe, but patients need frequent blood tests to monitor liver numbers and white blood cell counts.

Azathioprine AZA and 6-mercaptopurine (6MP)

These two medications are primarily used to maintain remission (Keep inflammation under control and prevent flares) in Crohn's' disease and ulcerative colitis. These medications typically take 3-4 months to show a full effect on the bowel inflammation.

Methotrexate

Methotrexate is used as a pill or injection to maintain remission in Crohn's disease. Methotrexate is also sometimes used in combination with biologics (see below).

Tofacitinib (Xeljanz®)

Tofacitinib is an oral medication that is approved for management of moderate to severe UC in adults. It works by blocking a pathway of inflammation called the JAK-STAT pathway. Although, this is not approved for children with IBD, it is sometimes used in children when other medications do not work.

Possible side effects include:

- Nausea or vomiting
- Diarrhea and abdominal discomfort
- Decreased ability to fight infections
- Fatigue or feeling tired
- Pancreatitis or inflammation of pancreas (typically presents with severe abdominal pain and vomiting)

Cyclosporine (Gengraf®, Neoral®, Restasis®, and Sandimmune®), Tacrolimus (Prograf®) and Sirolimus (Rapamune)

These medications work by suppressing immune system and are typically used for short-term to induce a remission in severe Crohn's disease and ulcerative colitis that is difficult to control with conventional treatments.

Typically, these medications need close monitoring of blood medication levels to maintain in a certain range, monitor kidney function and electrolytes.

These medications are associated with increased risk of infections and some children may need to be on antibiotics while on tacrolimus, sirolimus and cyclosporine.

Biologics

Biologics are complex proteins designed to bind and block specific targets and thus control inflammation. They are made partly or entirely from living sources, such as animal or human cells. They have active ingredients, such as antibodies and include a broad range of drugs differing in how they work and how they are given.

Biosimilar is a biologic that is manufactured based on an existing (originator) biologic but not an exact copy. Biosimilars work very similar to originator molecules and typically are given the same way. More information regarding biosimilars may be found [here](#).

Many types of biologics are available to treat IBD. These are given either injection (a shot under the skin) or infusion into a vein.

Routine follow-up care during treatment with blood tests and physical exam also helps to ensure safety. When prescribing biologics, the health care team will also think about how well the drug will work, how it is administered, the patient's preferences and the cost of the medication.

Anti-Tumor Necrosis Factor (TNF) agents or TNF inhibitors

Infliximab (Remicade®), Adalimumab (Humira®), Golimumab (Simponi®) Certolizumab pegol (Cimzia®)

Anti-tumor necrosis factor (anti-TNF) antibodies bind and block a chemical called tumor necrosis factor (TNF). TNF is thought to cause inflammation in the bowel and thus blocking this leads to control of inflammation and improvement in symptoms. It is also known to achieve mucosal healing. Examples include-FDA-approved for use in children with IBD-

- Infliximab (Remicade)
- Adalimumab (Humira)
- Infliximab-adba (Renflexis), Remicade biosimilar
- Infliximab-dyyb (Inflectra), Remicade biosimilar
- Infliximab- axxq (Avsola), Remicade biosimilar

Not FDA-approved but used sometimes in children when the above do not work or children become immune (develop antibodies) to the approved medications

- Certolizumab (Cimzia)
- Golimumab (Simponi)

Anti-TNF agents are considered one of the most effective medications in management of IBD. Although they are associated with side effects, the side effects are rare and the risks of these medications out weight the benefits. Some side effects include-

- Increased risk of infections
- Allergic reactions (risk is lower if medications are taken regularly as recommended by your doctor)
- Rarely increased risk of autoimmune reactions
- Extremely rarely lymphomas (lymph node cancers) and skin cancers

Vedolizumab (Entyvio®)

Vedolizumab blocks a protein called integrin on the surface of intestinal blood vessels and prevents inflammatory cells from moving into the intestines. Vedolizumab (anti-integrin antibody) is approved for management of adults with moderate to severe ulcerative colitis and Crohn's disease. Although, vedolizumab is not FDA-approved for children with IBD, it is typically used only when pediatric IBD does not respond to the medications that are approved by FDA.

Vedolizumab is given by intravenous infusion and takes weeks to months before you see an improvement in symptoms and is considered a very safe medication.

Ustekinumab (Stelara®)

Ustekinumab works by blocking two other mediators of inflammation called interleukin 12 and interleukin 23. It is typically given as intravenous infusion followed by injections (shots). It is associated with slight increased risk of infections especially, sinusitis but otherwise considered a very safe medication. Although, Ustekinumab is not FDA-approved for children with IBD, it is typically used only when pediatric IBD does not respond to the medications that are approved by FDA.

Taking Medication Please select a video Nutrition and IBD

Good nutrition is important in childhood and adolescence to support growth and development and help support the immune system.

IBD can affect nutrition in multiple ways-

- Active symptoms like poor appetite, diarrhea and abdominal pain will prevent children from eating
- Inflamed bowel (especially in Crohn's disease affecting small intestines) can lead to malabsorption
- Increased need for calories as expected with any chronic inflammatory state like IBD

Diet Therapies

There are various diet therapies that are used in treatment of IBD and often used in combination with medications.

- Exclusive enteral nutrition (EEN) which involves taking nutrition formula (eg- Pediasure, Ensure, KateFarms etc) for 100% of the calorie and nutrition needs for 8-12 weeks for induction. EEN is proven to induce remission in pediatric Crohn's disease and is as effective as corticosteroids
- Crohn's disease exclusion diet (CDED)- CDED is a three-phase elimination diet that is specifically designed for patients with Crohn's disease. Individuals on CDED restrict certain nutrients and food additives that are thought to have negative impact on the bacteria living in the gut. The diet typically involves whole foods with partial enteral nutrition (liquid formula) to achieve remission and reduce inflammation
- The specific carbohydrate diet (SCD) is a popular diet with some evidence that it can maintain remission in IBD, but it is not considered a proven treatment at this time. Further research is needed to better understand who SCD works best for and why.

Any special diet being considered should be discussed with your child's health care team to make sure it is safe and appropriate.

Eating healthy with IBD is the same as eating healthy without IBD, which means eating a variety of foods from each food group, in the right amounts, and in as natural form as possible. The key is to avoid heavily processed foods that are known to have food additives which could have negative impact and lead to intestinal inflammation.

During a "flare" it is important to make wise food choices and consider limiting intake of high-fat, greasy, or fried foods as well as sweets including sugar sweetened beverages, desserts, and juices. These foods typically do not have a high nutrient value (do not provide optimal nutrition) and could worsen symptoms. Some may worry about high-fiber foods such as raw fruits and vegetables, but these foods provide good nutrition and should only be limited if they cause or worsen symptoms.

Any suspected intolerance may improve as inflammation improves. For example, lactose intolerance could occur if a specific part of the small intestine (called the duodenum) is inflamed. However, the intolerance should improve as inflammation improves, and milk may be tolerated well once in remission. It can be helpful to keep a food journal if your child does not seem to tolerate certain foods. Discuss your concerns with your child's health care team.

Dietary Fiber

There may be a few specific situations that require a change in your child's diet. Dietary fiber may cause pain and block the intestine if it is narrowed by inflammation (stricture) or after surgery. A low-fiber diet can be helpful when inflammation of the intestines has narrowed the passageway. Again, these foods are generally healthy, and such changes in diet are temporary until inflammation improves.

Weight Loss

If your child is experiencing weight loss, a high-calorie, high-protein diet may be beneficial. Dairy and meat food groups (including animal and non-animal foods) provide good sources of calories and protein. For those having trouble eating, nutrition shakes can be useful in supplementing the nutrients they miss. If your child is unable to eat or drink enough nutrition, a temporary feeding tube can be used to alleviate the pressure of eating and ensure your child gets necessary nutrition. Remember that weight loss could be a sign of active inflammation, so your child's medical team should be informed if weight loss occurs.

Vitamins, Minerals, Herbs and Medications

It is important to let your child's physician know if you are giving your child any over-the-counter medicines, multivitamins, minerals, or herbal supplements, as they can possibly interact with medications.

It is usually recommended that your child take a multivitamin with iron. If your child's iron level is low, the physician may recommend an additional iron supplement either as pill or intravenous infusion. Additional folate may be recommended if your child is on a medication that interferes with folic acid absorption (methotrexate and sulfasalazine).

Calcium and vitamin D are important, especially during the critical time of childhood and adolescence, for achieving optimal bone health. Your child may also need additional calcium and vitamin D, especially if they are taking steroids. There could be other circumstances that require additional vitamins and/or minerals, so it is important to discuss any questions about nutrition with your child's physician or dietitian.

Sometimes your doctor may recommend you take probiotics and certain nutrition supplements like curcumin (turmeric). Please discuss with your doctor if you are interested to learn more about these.

Overall, nutrition plays an important role in treatment of IBD. Proper nutrition may enable your child to reach their full growth potential and live a healthier life

Resources

Videos

What is Crohn's Disease?

<https://youtu.be/B8ryJ9P38B8> (<https://youtu.be/B8ryJ9P38B8>)

What is Ulcerative Colitis?

<https://youtu.be/3-BEdeb8kmE> (<https://youtu.be/3-BEdeb8kmE>)

Treatment Options

<https://youtu.be/Mp9br6olPIU> (<https://youtu.be/Mp9br6olPIU>)

Taking Medications

<https://youtu.be/-zHGpj1iz84> (<https://youtu.be/-zHGpj1iz84>)

Types of Medications

Aminosalicylates: https://youtu.be/t7GSufR_cJc (https://youtu.be/t7GSufR_cJc)

Corticosteroids: <https://youtu.be/fnLxFvPHdLY> (<https://youtu.be/fnLxFvPHdLY>)

Immunomodulators: <https://youtu.be/tml56KoplZU> (<https://youtu.be/tml56KoplZU>)

Antibiotics: <https://youtu.be/ZKagvmZJLYQ> (<https://youtu.be/ZKagvmZJLYQ>)

Biologics: <https://youtu.be/iJMcPtNSxks> (<https://youtu.be/iJMcPtNSxks>)

Surgery

<https://youtu.be/ZRIReKGb7CQ> (<https://youtu.be/ZRIReKGb7CQ>)

<https://youtu.be/MLyakCY5bBs> (<https://youtu.be/MLyakCY5bBs>)

Nutrition and IBD

<https://youtu.be/uxEGDsaSNhg> (<https://youtu.be/uxEGDsaSNhg>)

https://youtu.be/Vg_rVdouuz4 (https://youtu.be/Vg_rVdouuz4)

<https://youtu.be/rsjX4m91PkM> (<https://youtu.be/rsjX4m91PkM>)

<https://youtu.be/-yT-UMQ-YXk> (<https://youtu.be/-yT-UMQ-YXk>)

Health guidance for IBD

https://youtu.be/tTSqHS_vyO8 (https://youtu.be/tTSqHS_vyO8)

Coping/Mental Health

<https://youtu.be/6nPSNJqKtso> (<https://youtu.be/6nPSNJqKtso>)

Podcasts

Maintaining Healthy Nutrition in Pediatric IBD Patients

During this series, we will discuss the important role diet plays in the management of IBD focusing on maintenance of good nutrition, enteral nutritional therapy as well as the Specific Carbohydrate Diet. You will hear from medical professionals as well as two parents who have first-hand experience implementing enteral nutritional therapy and the Specific Carbohydrate Diet. Additionally, we have included a podcast on navigating independence when transitioning to college or the work force.

Surgical Options for IBD

Surgery for both Crohn's disease and ulcerative colitis can be an integral part of therapy and are not necessarily a last resort. The options for surgery differ between UC and Crohn's disease, and there are many types of surgery depending on the location of disease in intestines, the type of complication and severity of the illness.

Surgery is best used in conjunction with medical therapy. In selected cases, surgery may be best early in the disease. Overall, many patients with IBD will require some type of surgical procedure during their illness. The goals of surgery are to reduce or resolve symptoms and to improve general health, nutritional status, growth, and sexual development, while trying to preserve as much bowel as possible.

The decision about surgical therapy should be based on clinical history of the patient, with additional information from radiologic (MRI, CT, ultrasound, or X-ray) and endoscopic tests. Patients and their families should discuss this decision with their entire health care team, which usually consists of

multiple specialists including a pediatric gastroenterologist, pediatric surgeon, nutritionist, and psychologist.

General Terms

There are two main techniques used to perform IBD surgery: laparotomy and laparoscopy.

Laparotomy, or open surgery, is a more traditional method using one abdominal incision.

Laparoscopy uses instruments inserted into the abdominal cavity through several small openings, thus leaving several very small scars. When performed by a surgeon familiar with the technique, laparoscopy allows for an easier and faster recovery. Today, many operations for IBD can be performed laparoscopically. Ultimately, it is safest for the surgeon to make the final decision on which type of procedure to perform.

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