



**The
Emily
Center**



Inflammatory Bowel Disease (IBD) Family Handbook

#1856

How to Care for Your Child with Inflammatory Bowel Disease (IBD)

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1. I can tell you about Inflammatory Bowel Disease (IBD)

What is Inflammatory Bowel Disease (IBD)?

Inflammatory Bowel Disease (**IBD**) is a chronic condition of the intestines (**bowels**) or digestive tract that causes irritation and swelling (**inflammation**) in the lining. The IBD program at Phoenix Children's Hospital is dedicated to helping you and your child find treatments and support to control symptoms and promote a healthy quality of life. When a child is diagnosed with a serious condition, parents often feel out of control because they don't understand everything that is happening. However, once they learn about the illness and how to perform home care skills, parents get their sense of control back.

Perhaps you, too, are feeling out of control and overwhelmed because you need to learn about your child's IBD diagnosis. This information may seem like too much to handle right now, but don't give up. Like other families, you will also be able to take care of your child's IBD. We are here to help you through your child's IBD journey.

IBD will continue to be present during your child's life. It may get better or worse from time to time depending on how well the medicines work, other illnesses, and your child's overall health. Even though the cause of IBD is still not known, we do have many treatments available to help your child live an active and healthy life.

The IBD team at Phoenix Children's follows the hospital's vision to provide hope, healing, and the highest quality care available for your child. We look forward to working with you to help your child lead a healthy and active life.

Definitions:

IBD: a chronic inflammation or irritation of the stomach, small intestine, and/or colon. It is an autoimmune disorder.

Stomach: stores, mixes, and empties food during digestion.

Small intestine: receives partially digested food from the stomach and continues to further digest food (more chemical digestion - enzymes, bile); absorbs nutrients; empties remaining contents into large intestines/colon.

Colon: completes absorption of sodium, potassium, and water. Removes undigested waste and water.

How does IBD happen?

Normally, there are elements in the immune system that protect your child from infections. In IBD, the immune system does not act (**respond**) in a normal way. It accidentally sees normal material in the digestive tract as unfamiliar (**foreign**) to the body. When this happens, the body sends white blood cells into the lining of the intestines, where they develop into signs of irritation and inflammation (**swelling**). In some cases, this can cause sores (**ulcers**) in the tissue, a hole (**perforation**) in the tissue, bleeding, pus, and even scarring.

What is a Journey Board?

The purpose of a Journey Board is to provide support for patient and family education. It supports the idea of family-centered care. The journey board is available in a printed handout or an internet app (**application**). If you do not have internet access, please let us know and we can print copies of the information for you. You can contact us with any questions.

The Journey Board shows you all the topics to be discussed. While your child is in the hospital, your child may be started on the treatment or medicines needed to get the IBD under control. Your child's caregivers will need to be at the hospital every day to learn the basics. After leaving the hospital, your family will continue to talk to and meet with our IBD Team. These topics will be reinforced again later in the IBD clinic. We will teach you the skills to get and keep your child's IBD in control (**remission**). We will help you become comfortable and confident in your ability to manage your child's IBD, especially to know when your child is healthy or actually having a flare up. We are here to help you on this IBD journey.

Common Abbreviations you may hear about IBD:

BE Barium Enema
BMP Basic Metabolic Panel
CBC/CBCD Complete Blood Count/Complete Blood Count with Differential
CMP Complete Metabolic Panel
CD Crohn's disease
COLON Large Intestine or Colonoscopy
CRP C. Reactive Protein
CT Computerized Tomography
DEXA Bone Density Scan
ED/ER Emergency Department/Emergency Room
EGD Esophagogastroduodenoscopy
ESR Erythrocyte Sedimentation Rate
GI Gastrointestinal
IBD Inflammatory Bowel Disease
IBS Irritable Bowel Syndrome
IC Indeterminate Colitis
ID Infectious Disease
IV Intravenous
KUB Abdominal X-ray (Kidneys, Ureters, Bladder)
LFT Liver Function Test
MRE Magnetic Resonance Enterography
MRI Magnetic Resonance Imaging
NPO Nothing by Mouth (No Eating or Drinking)
NSAID Non-Steroidal Anti-Inflammatory Drug
OTC Over the Counter
PA Prior Authorization
PCP Primary Care Provider (Pediatrician or Family Practice Physician)
PRN Take only as needed (regarding medicines)
SCOPE Endoscopy
UA Urine Analysis
UC Ulcerative Colitis
UGI Upper GI
UGISBFT Upper GI with Small Bowel Follow-Through
US Ultrasound

Now that you've read this:

- Tell your nurse or doctor what IBD is. (Check when done.)
- Tell your nurse or doctor how you will use your Journey Board on your child's IBD Journey. (Check when done.)

2. I can tell you what form of IBD my child has

First, understand there is nothing you or your child did that gave him or her IBD. There is nothing you could have done differently to prevent your child from developing IBD. We will explain the basics about IBD, and show you how to safely care for your child at home.

What are the different types of IBD?

There are two main forms of IBD: Crohn's disease (**CD**) and Ulcerative Colitis (**UC**).

Crohn's disease (CD) is a chronic disease that causes irritation and swelling (**inflammation**) in the lining of your digestive (also called the **Gastrointestinal or GI**) tract. This often spreads deeper into the layers of tissue in the wall of the intestines. CD can cause symptoms of belly (**abdominal**) pain and diarrhea which may be bloody. The areas of irritation and inflammation can show up anywhere from the mouth to the anus. CD may form an area of narrowing (**strictures**) in the GI tract. There may be areas of healthy tissue in between. Sometimes, an abnormal connection (**fistula**) between the GI tract and other areas or a hole (**perforation**) in the tissue may form.

Ulcerative colitis (UC) is a chronic disease of the large intestine (**colon**) in which the lining of the colon becomes inflamed. This condition causes chronic inflammation and sores (**ulcers**) in the inner lining of the large intestine (**colon**) and rectum. The combination of inflammation and ulcers can cause belly (**abdominal**) pain, blood in stools and other symptoms outside the GI tract.

Indeterminate colitis (IC) There are times, even after thorough testing, when your GI doctor is unable to tell whether your child's IBD is Crohn's disease or ulcerative colitis. This usually occurs when there are IBD signs that involve the large intestines (like UC), but also has signs that looks like CD. These patients may

be told the diagnosis of indeterminate colitis or IBD unclassified. Your GI doctor may look into this again later on to decide if the diagnosis is either Crohn's disease or ulcerative colitis.

Now that you've read this:

- Tell your nurse or doctor what form of IBD your child has and what that means. (Check when done.)

3. I can tell you the signs of IBD and what a flare is

What are signs I may see with both CD and UC conditions?

- Diarrhea that may also have blood in it
- Fatigue
- Fever
- Loss of appetite and weight loss
- Belly (**abdominal**) pain
- Intense cramps and sudden urges to use the restroom
- Delays in physical growth
- Chronic pain, sometimes in joints
- Mouth sores
- Difficulty paying attention at work or school due to the any of the above signs

What is a flare or flare up?

There are times with IBD when your child does not feel well and may be having a **flare**. A flare or flare-up occurs when IBD symptoms suddenly get worse.

What are signs of a flare?

Signs of a flare can range from mild to severe. They are often similar to what children experience when they are first diagnosed with IBD. While some symptoms strongly suggest a flare, others are less specific and may be a sign of a virus or another illness. Watching for signs of a flare is important.

Signs of a flare can include:

- Belly (**abdominal**) pain or cramping
- Diarrhea with or without blood
- Bloody stools
- Eye pain or redness
- Fever above 101 °F for more than one day
- Joint pain
- Joint swelling
- Mouth sores (**ulcers**)
- Nausea
- Tired (**fatigue**)
- Weight loss that is not planned
- Vomiting

What to do:



- Call the GI team if your child has any of the signs of a flare listed above.
- Call the GI team if signs of a flare do not go away or get worse.
- Call the GI team right away if you see:
 - Bloody diarrhea
 - Bumps on the arms or legs that are:
 - Painful
 - The size of a coin
 - Black or red in color

For more information, ask your nurse or doctor for this handout:

- **Dehydration #13**

Now that you've read this:

- Tell your nurse or doctor the signs of IBD. (Check when done.)
- Tell your nurse or doctor what a flare is. (Check when done.)
- Tell your nurse or doctor how you will know your child is having a flare. (Check when done.)

4. I can tell you what medical tests my child is getting and what they are for

Your GI doctor needs to decide (**diagnose**) if your child has IBD based on medical tests before treatment can be started. There will be a work-up to help make the diagnosis. Medical tests will be done to find out what type of IBD your child has. This may include:

- Blood tests
- Stool studies
- Radiology tests (such as x-rays)
- Endoscopy procedures

Your child will need these medical tests and procedures done from time to time throughout his or her life. Even though this may be stressful for your child, it is important that he or she understands the reasons that medical tests are needed.

Our Child Life department can offer activities based on your child's age and school level. A Child Life Specialist can support your child during the hospital stay. A Child Life Specialist can help your child cope with fear, anxiety and discomfort that may occur with medical testing or during the hospital stay. Ask a member of the GI team to help you involve a Child Life Specialist during your child's IBD journey.

Blood Tests

Blood tests (**lab tests or labs**) may be ordered to tell us how the body is working. It may take a few hours or up to many weeks to get the results back from the lab to your GI doctor. Your GI doctor needs to review the results and make a plan of care for your child. A member from our GI team will call you back with these results when they are available.

Here is a list of the most common blood tests that you may hear the GI team talk about:

Common Labs

- CBC - helps identify low blood count (**anemia**) and swelling (**inflammation**)
- BMP/CMP - helps identify related nutritional and electrolyte problems
- ESR and CRP - helps identify inflammation
- Metabolites - levels to help identify if IBD medicine is working

The following labs are less common, but may be ordered at some point during your child's IBD journey:

- Hemoglobin (**HGB**) is the part of the red blood cell that carries oxygen. Red blood cell levels may go down due to bleeding. Individuals with any type of long-term (**chronic**) illness may not make as many red blood cells. Children who have low hemoglobin may appear pale or tired (**fatigued**).
- White Blood Cells (**WBCs**) help fight infections. Some of the medicines used to treat IBD can slow down how the bone marrow makes WBCs. This may increase the chances to get an infection.
- Platelets (**PLT**) are blood cells that help form clots to stop bleeding. Platelets can be low during illness when the bone marrow makes less. Platelets can be high when inflamed tissues are present.
- Total Serum Protein or Albumin (**ALB**) is a test to count proteins in the body. Inflamed tissue can let these proteins leak into the intestine. Low albumin can cause mild swelling of the face, feet, belly and scrotum in boys.
- Liver Function Tests or Complete Metabolic Panel (**CMP**): There are several different tests to check enzymes made by the liver. Enzyme levels may be increased by inflammation, blockages in the liver, infection, and some medicines.
- Blood Urea Nitrogen/Creatinine (**BUN/CR**) are enzymes that show how the kidneys are working. These enzymes can be high or low based on how the kidneys are working. This is called the hydration status. Some medicines may also affect these test results.
- Glucose (**GLU**) is the blood sugar level. This level can be high when a child is on a steroid medicine such as prednisone.
- 6 TG or Thiopurine Metabolites shows the level of medicine in the body for either 6-Mercaptopurine (**6 MP**) or azathioprine (**Imuran**®). This level helps

the doctor know if the medicine is working to treat the IBD. It also shows if the medicine is being taken as directed.

- C-Reactive Protein (**CRP**) is a protein that is made by the liver and released into the blood when there is swelling (**inflammation**) in the body. Your child's doctor may order this test to check the level of inflammation and check how well your child's body is responding to the treatments.
- Erythrocyte Sedimentation Rate (**ESR**) is also called the sed rate. This is a test to check ongoing (**long-term**) inflammation in your child's body. Your doctor may order this test along with CRP to check for inflammation markers and see how your child is responding to treatment.

Stool Tests

Stool tests are often ordered when your child has an increase in IBD symptoms. Testing the stool will help find out if it is due to an infection or a flare of your child's IBD. You may be asked to collect the stool at home, and then bring the stool samples to the PCH lab or a lab near your home to be tested.

Common types of stool tests:

Clostridium Difficile (C-Diff.) is a germ (**bacteria**) that may be found in the intestines. Symptoms often include diarrhea and blood in the stool. Sometimes antibiotics that are used to treat another infection kill the good bacteria and allow C-Diff. to grow out of control.

Ova and Parasites tests check for an infection caused by parasites. Symptoms of these infections are often like IBD symptoms. Most often, individuals get these types of infections in places such as a daycare, public pools, camping grounds or lakes.

Stool Cultures test for bacterial infections in the intestines.

Hemocult Stools tests for tiny amounts of blood found in the stool.

Calprotectin/Lactoferrin is a stool test that checks for inflamed tissue in the GI tract.

When you pick up your stool container(s), ask the lab staff if the stool test has special instructions. Some stool studies collected at home may need to be kept in a plastic bag in the refrigerator before bringing them back to the lab for testing.

Radiology Tests

There are many radiology (**imaging**) studies that are useful in caring for patients with IBD.

Common radiology tests include:

Abdominal X-Rays (KUB, Flat Plate) are x-rays that look for air, fluid and stool in the intestines.

Computerized Tomography (CT) is a more detailed x-ray to help decide what is normal bowel, and what is abnormal. Instructions to prepare for the CT will be called to you when the radiology staff schedule the exam. The radiology team will give you more details about what to expect during the CT study. To take the best picture, a special contrast may be given in a drink or through an intravenous (**IV**) site.

Ultrasound (US) uses sound waves to make a picture of the inside the body. Gel is applied to the belly (**abdomen**) and a special wand is passed over the area. To prepare for the test, your child should not eat or drink anything by mouth (**NPO status**) for 4-6 hours before the test.

Bone Density Study (DEXA Scan) shows how thick or thin, and how strong the bones are. Thinning of the bones can be caused by disease, poor diet or medicines. An x-ray of the entire body will be done. This test takes approximately 15 minutes. Your child will need to lie still during this study.

Magnetic Resonance Enterography (MRE) uses a strong magnet that makes pictures (**images**) of the GI tract. MRE staff will call you to give you instructions to prepare for this test. Tell them if your child has any metal in his or her body, or if your child has ever had kidney (**renal**) problems. You will need to arrive 2 hours prior to the MRE. This allows time for your child to drink the special contrast needed for the study.

Endoscopy

An endoscopy is a procedure done to help decide (**diagnose**) your child's type of IBD. This procedure also checks to see if the lining of your child's intestines is

healthy or inflamed. Based on your child's symptoms and lab results, your doctor may choose an upper endoscopy (**esophagogastroduodenoscopy or EGD**) and/or lower intestine endoscopy (**colonoscopy**) to be done. The doctor can look at the intestine with a small camera and take small tissue samples (**biopsies**) from the intestinal lining to send for microscopic testing (**pathology**). This helps the doctor to make the best treatment plan for your child

The GI procedure scheduler will call you to schedule the endoscopy procedure. Several days prior to the procedure date, a member of the GI team will email you the instructions. If you do not have an email address, you will receive a phone call instead. The instructions will explain the steps to get ready. This is often called the **prep or preparation** for the procedure. This will include when to stop eating food, when your child can only have clear liquids to drink, and when your child should not take anything by mouth (**NPO status**).

If your child's procedure includes a colonoscopy, the instructions will include the steps for when and how to take the stool softening medicines to clean out the intestines before the procedure. This is often called a **clean out**. It is important to follow the clean out directions carefully. Call your GI doctor with any questions or concerns about the clean out instructions.

For more information, ask your nurse or doctor for these handouts:

Upper Endoscopy or EGD # 105

Colonoscopy #116

CT Scan #93

Now that you've read this:

- Tell your nurse or doctor the name of each test, how each test is done, and what it is looking for. (Check when done.)
- Tell your nurse or doctor the meaning of the results of your child's tests. (Check when done).

5. I can tell you about my child's treatments

Goals of IBD treatment are to work with you and your child to:

- control IBD symptoms
- promote healthy nutrition and adequate growth
- encourage an active lifestyle
- provide access to support and resources
- develop a treatment plan that works best for your child
- prevent complications from IBD

What can I do to help meet these goals?

- Bring your child to the GI clinic for follow-up visits. This is usually every three to four months unless your doctor tells you differently.
- Be honest with us about how your child is doing. This information is an important part of making a treatment plan that is best for your child.
- Ask questions if you do not understand. Encourage your child to ask questions too.
- Things to bring to each clinic visit:
 - Name and dose of all medicine your child takes. This includes all prescription medicines, vitamins, herbal products, and over-the-counter medicines.
 - A list of signs and symptoms your child has had since the last visit
 - A list of any questions you or your child have
- Get your child's tests done on time as ordered by your child's doctor. This will help to keep track of your child's IBD and to know if the treatment plan is working. Blood tests may be done when you come for your child's clinic visit or at a lab close to your home.
- Schedule an annual eye (**ophthalmology**) exam as directed by your child's GI doctor.
- Schedule an annual skin (**dermatology**) exam as directed by your child's GI doctor.

Important information about taking IBD medicine safely:

- Your child needs to take each medicine as ordered, even when there are no signs or symptoms. This is the best way to prevent flares.
- Tell us if your child develops any allergies.
- Call your pharmacy for medicine refills at least 4 days before more medicine is needed. Your pharmacy will call our office if an order for more refills is needed.
- If your child misses a dose of medicine, have your child take it as soon as he or she remembers. If it is almost time for the next dose, he or she should skip it and take the next regularly scheduled dose. Do not take a double dose of medicine.
 - For IBD medicines that are three times per day: take them at breakfast, after school, and at bedtime.
 - For IBD medicines that are four times per day: take them at breakfast, lunch, dinner and at bedtime.
- Let us know if your child has a hard time taking his or her medicine as ordered. For example, if your child has a hard time swallowing pills, we will work with your child to find an option that works best.
- Tell us if the cost of medicine is preventing you from getting it for your child.
- If your child has a sudden (**acute**) illness that is not related to IBD, contact your PCP for guidance. If your PCP orders an antibiotic, have the PCP consult with your child's GI doctor first. Some antibiotics can cause an IBD flare. There are times when antibiotics should be avoided, unless absolutely necessary. The GI doctor can assist with the best treatment choices.
- Schedule colonoscopy procedures as ordered by your child's doctor. People with Crohn's disease of the colon or ulcerative colitis have a higher risk for colon and rectal (colorectal) cancer. The risk increases the longer a person lives with the disease. The risk is also related to the amount of colon with IBD disease and the severity of the disease. Because of this increased risk, people with IBD are encouraged to have more frequent colonoscopies compared to healthy individuals. To further decrease this risk, it is important for your child to take all medicine as ordered by your child's GI doctor and come to all clinic appointments as scheduled.

What to expect if your child needs to come to the hospital:

It is possible that your child will need to be admitted to the hospital when symptoms are severe. Here are a few guidelines:

- You will be able to visit your child 24 hours per day in our inpatient units. Parents may sleep in your child's room at night.
- Brothers, sisters and friends may visit during regular visiting hours, after the hospital nurse has made sure they are not sick. Visitor restrictions may apply during RSV, cold and flu season.
- Things your child can bring from home to feel more comfortable:
 - His or her own clothes
 - Games and toys
 - A pillow and blanket
- Your child may be seen by a different GI doctor during your child's hospital stay. Your child's GI doctor will be updated regularly with your child's status.

Nutritional therapy

This therapy is also known as enteral therapy. Nutritional therapy is used to help bring about remission from IBD. These special formulas contain all the necessary nutrients, vitamins and minerals to help with healing and growth. Formulas can be taken by mouth, but usually are given through a nasogastric or NG tube. This is a tube passed through the nose into the stomach to feed your child.

For more information, ask your nurse or doctor for these handouts:

How to Care for Your Child with a Nasogastric (NG) Tube, #1824

Our Journey with Tube Feeding Journey Board #1882

Our Journey with Tube Feeding App Download Instructions #1883

Will surgery be needed for treatment of my child's IBD?

Surgery is not required for every child with IBD. IBD can often be managed with lifestyle changes, diet and medicine. If the medical plan of care to treat your child's IBD is not working, your GI doctor may refer your child to a Surgeon for evaluation of surgical treatment options.

Now that you've read this:

- Tell your nurse or doctor about your child's treatments for IBD.
(Check when done.)

6. I can tell you about my child's medicines

What are common medicines to treat IBD?

Your child will need to take medicines as prescribed by the GI doctor. Do not change the dose of medicine or stop the medicine unless told to do so by a member of the GI team. Ask your pharmacist if you need more detailed information about each medicine. Your GI doctor will closely check blood tests while your child is taking these medicines. Blood tests help find out how your child's body is responding to the treatment medicines. Blood tests also check for side effects from medicines.

Common categories of medicines to treat IBD:

Aminosalicylates (5-ASAs):

These medicines fight inflammation (**anti-inflammatory**). Aminosalicylates or 5-ASAs are similar to aspirin. They help start healing, reduce inflammation, and decrease pain and discomfort. This class of drugs is absorbed in different parts of the GI tract. This means the doctor will pick a specific 5-ASA medicine because it will work best where the disease is located in your child. This class of drugs should not be taken if your child has an allergy to sulfa. This is the list of common 5-ASA medicines:

- Pentasa[®] (**mesalamine**)
- Lialda[®] (**mesalamine**)
- Apriso[®] (**mesalamine**)
- Colazal[®] (**balsalazide**)
- Delzicol[®] (**mesalamine**)
- Asacol HD[®] (**mesalamine**)
- Azulfidine[®] (**sulfasalazine**)
- Canasa[®] (**mesalamine**)
- Rowasa[®] (**mesalamine**)

Corticosteroids or Steroids:

This category of drugs is often used since they may bring on a rapid improvement. They will help control most of the IBD symptoms within a short period of time. The GI doctor must be careful with these drugs. There are possible side effects

which may increase and become more serious the longer the medicine is taken. That is why this medicine may only be taken for short periods of time. A sudden stop in steroids can also bring on dangerous side effects. Your child's GI doctor will talk to you about how to safely decrease (**wean**) the dose until your child is off of this medicine. Always follow your child's weaning schedule as ordered by your GI doctor. Some examples of corticosteroids or steroids include:

- prednisone
- Orapred® (**prednisolone**)
- hydrocortisone
- Entocort® (**budesonide**)
- Cortifoam® (**hydrocortisone**)
- methylprednisolone

Immunomodulators:

These are medicines that help to alter the immune system. IBD is a condition that causes an abnormal immune response to a normal body part. This abnormal immune response is why IBD is called an **autoimmune disease**. Immunomodulators help change the immune response to work correctly. Your child's doctor will order blood testing to monitor the drug levels of these medicines in your child's body to make sure they are in a safe range. Examples of immunomodulators include:

- Imuran® (**azathioprine**)
- mercaptopurine (**also called 6-Mercaptopurine or 6 MP**)
- methotrexate
- Prograf® (**tacrolimus**)

Biologics:

These medicines are the newer choices for treatment of IBD. Currently, Remicade® and Humira® have Federal Drug Administration (**FDA**) approval for use in children. Some biologics are approved in adults, but are not yet approved in children. In some cases, the GI doctor may still be able to prescribe these medicines in children. Common medicines in this category include:

- Remicade® (**infliximab**)
- Humira® (**adalimumab**)

- Cimzia® (**certolizumab pegol**)
- Entyvio® (**vedolizumab**)
- Stelara® (**ustekinumab**)

Antibiotics:

Antibiotics have been found to be effective in the treatment of IBD. They help to bring IBD flares under control. A healthy immune system protects the body from illnesses caused by germs (**bacteria**). Because the immune system is altered with IBD, your child may need to take antibiotics to help treat infections in the intestines. Antibiotics may help to reduce inflammation by fighting off harmful bacteria in the intestines.

- Flagyl® (**metronidazole**)
- Cipro® (**ciprofloxacin**)

Probiotics:

The body has healthy germs (**good bacteria**) in the intestines that assist with digesting food and keeping the GI tract healthy. When your child has IBD, there may be times when the intestines needs a boost of these good bacteria. A member of the GI team may suggest that your child start a probiotic. Ask your GI team if this would be beneficial for your child.

What are the possible side effects of these IBD medicines?

The common side effects of IBD medicines may include:

- Nausea
- Belly pain
- Decreased blood counts
- Liver irritation
- Change in liver function
- Increased risk to get an infection

The use of certain medicines for IBD may increase the risk for lymphoma. A lymphoma is a blood cancer that starts in the lymphatic system. Although this may sound concerning, the overall risk is very low. Contact the GI doctor or your pharmacy for any questions or concerns.

Remember, it is always important to follow the directions from your GI doctor to take medicines as ordered. This will help decrease some of the possible side effects. Also, get lab orders done when requested. This allows the GI doctor to monitor the health of your child and make sure the medicine is working.

Medicines to avoid:

There are many medicines available to help relieve pain. Your child should avoid over-the-counter (**OTC**) and prescription medicines in this category that contain aspirin or nonsteroidal anti-inflammatory drugs (**NSAIDs**). These medicines have been shown to cause irritation sores (**ulcerations**) in the intestines. This irritation can increase the chance of a flare. Your child should not take these products unless ordered by your GI doctor.

Examples of aspirin products and NSAID drugs to avoid include:

- Advil® (**ibuprofen**)
- Motrin® (**ibuprofen**)
- Aleve® (**naproxen**)
- Anaprox® (**naproxen**)
- Naprosyn® (**naproxen**)
- Daypro® (**oxaprozin**)

Products such as Tylenol® (**acetaminophen**) are okay to take instead.

For more information, ask your nurse or doctor for these handouts:

About Taking Medicines #24

Always Have Medicine #909

Medicines to Take #337

Medicine List #786

Now that you've read this:

- Tell your nurse or doctor the name of each medicine you will give your child at home. (Check when done.)
- Tell your nurse or doctor why each medicine is given. (Check when done.)
- Tell your nurse or doctor when and how much of each medicine is given. (Check when done.)
- Show your nurse or doctor how you will give each medicine to your child. (Check when done.)

- Tell your nurse or doctor if there are any medicines or foods your child should not have when taking each medicine. (Check when done.)
- Tell your nurse or doctor the possible side effects of each medicine. (Check when done.)
- Tell your nurse or doctor what you will do if your child has any of these side effects. (Check when done.)
- Tell your nurse or doctor who you will call if you have a question or concern about a medicine. (Check when done.)

7. I can tell you how what my child eats affects this condition

How does the food my child eats affect IBD?

What your child eats may affect IBD symptoms. IBD is not caused by what your child eats. Your child's IBD disease is unique. Certain foods or ingredients may cause (**trigger**) a reaction in the intestines. Trigger foods are foods that may cause an increase in IBD symptoms. Keeping track of any trigger foods may be helpful.

With IBD, your child's growth is something we watch closely. When the wall of the intestines is inflamed, the lining can lose proteins and other substances needed by the body to grow. When your child's intestines are inflamed, he or she may not want to eat as much. This is because your child may have belly pain or not have an appetite. When IBD disease is active (also called a **flare**), your child may need extra nutrients or supplements to meet his or her nutrition goals.

Call your child's GI doctor if there are any changes in how much your child eats.

Children with IBD have a higher risk for the health of their bones. Make sure your child gets enough calcium and vitamin D every day. Talk with our GI dietitian if you have any concerns about how to make sure your child gets enough calcium each day. Ways to make sure your child gets enough calcium each day include:

- eating dairy products, such as milk and cheese
- taking a daily calcium supplement
- taking daily Vitamin D as directed

Now that you've read this:

- Tell your nurse or doctor what your child can eat to help this condition. (Check when done.)
- Tell your nurse or doctor what diet changes your child can make to decrease triggers from happening. (Check when done.)
- Tell your nurse or doctor what will be difficult about these diet changes and how you will overcome these difficulties. (Check when done.)

8. I can tell you how to manage my child's pain

Everybody feels pain sometimes. Pain can be useful. When we have an injury, pain keeps us from hurting ourselves more. When we have a disease such as IBD, pain tells us something has changed.

There are common reasons your child may have belly pain:

- Change in diet
- Constipation
- Diarrhea
- Acid Reflux
- Gas pain
- IBD flare
- Surgical procedure

Pain changes the way we think, feel and act. Pain that lasts a long time may hurt our relationships with our family and friends. Pain can keep us from going to school and having fun. Pain that lasts a long time can hurt our minds as well as our bodies. Pain can make people feel sad, anxious, or depressed.

It is okay to reach out to the GI team when there is a change in your child's pain. If your child has just had a surgical procedure, reach out to your child's Surgeon. They may offer helpful suggestions including ordering labs or radiology tests to decide if the pain needs further treatment or care.

For more information, ask you GI doctor or Nurse for the following handouts:

About Pain: #472

Helping the Hurt at Home #1249

Now that you've read this:

- Tell your nurse or doctor how you will know when your child is in pain.
(Check when done.)
- Tell your nurse or doctor the best ways to comfort your child.
(Check when done.)

9. I can tell you about my child's IBD team

Sometimes your child will have a clinic appointment with the GI team which includes the doctor, the nurse, and the dietitian. Other appointments will be scheduled with a larger group called the IBD team. Our IBD clinic uses a team approach to evaluate, diagnose and create a treatment plan for children and adolescents with IBD in a family-centered care setting. At both types of appointments, our team will work with you and your child to best meet the physical, emotional, behavioral, financial and social needs of your family.

Your Child's IBD Team:

Gastroenterologist (GI doctor): _____

GI Nurse: _____

IBD Nurse: _____

Dietitian: _____

Surgeon: _____

Research Coordinator: _____

Psychologist: _____

Social Worker: _____

Pharmacy: _____

Homecare Company: _____

GI Clinic Information

- GI clinic visits should occur every 2-6 months. Your GI doctor will tell you how often to make your clinic appointments.
- Schedule all procedures, lab work, and referrals as ordered to prevent a delay in your child's care.
- Schedule yearly eye exams to identify early signs of swelling (**inflammation**) of the middle layer of the eye (**uveitis**), as directed by your GI doctor.
- Schedule yearly bone density (**DEXA scan**) x-ray to detect early signs of thinning of the bones (**osteopenia**).
- Get yearly flu (**Influenza**) shot. Your child should get a flu shot (**vaccine**) each year.
- Talk to your PCP and GI doctor about vaccines to avoid while taking IBD medicine.

To make a Clinic appointment:

Call the GI clinic at Phoenix Children's Hospital: (602) 933-0940. Pick option #2 to talk to the GI scheduler.

Prescription Refills:

For medicine refills, call your pharmacy directly. Ask the pharmacy to send requests for refills electronically to your GI doctor.

Now that you've read this:

- Tell your nurse or doctor the services the Primary Care Physician (PCP) manages for your child. (Check when done.)
- Tell your nurse or doctor about the services the PCH Gastrointestinal (GI) Clinic manages for your child. (Check when done.)
- Tell your nurse or doctor where you will fill your child's prescriptions. (Check when done.)
- Tell your nurse or doctor how you will get prescription refills. (Check when done.)
- Tell your nurse or doctor who you will call if your child needs medical supplies. (Check when done.)

10. I can tell you about additional care and resources to help my child stay healthy

General Healthcare

The GI team will work closely with you and your child's primary care physician (PCP) to take care of his or her IBD. Your child's GI doctor will keep the PCP updated about your child's progress with his or her IBD. Keep in mind, your child's PCP will continue to be in charge of your child's overall health care plan.

Things to know about childhood illness and immunizations:

If your child is exposed to chicken pox (**varicella**) or gets chicken pox disease, call the GI team right away. A dose of chicken pox medicine (**varicella zoster immune globulin or VZIG**) may be needed. This medicine may help make the chicken pox rash less severe. Since your child is taking medicine that weakens (**suppresses**) the immune system, it is important for us to know this information.

Talk to your PCP and GI doctor before your child receives any vaccinations. Vaccines that are "live" forms such as measles/mump/rubella (**MMR**) and chicken pox are not recommended for patients taking certain medicines to treat IBD.

Health Maintenance:

- Some IBD medicines can cause:
 - Sensitivity to the sun
 - An increased risk for skin cancer
 - An increased risk for cancer of the lymph nodes (**lymphoma**)
 - Thinning of the bones
- Always wear sunscreen when outside for long periods of time.
- Check with the GI doctor to see if a bone density scan (**DEXA**) is right for your child.
- Schedule an eye exam for your child every year.
- If your child has any skin concerns or rashes, talk with your child's PCP or GI doctor about a referral to a skin doctor (**dermatologist**).

- Continue to see your child's PCP for annual checkups, or sooner based on your child's plan of care.

For more information, ask your GI doctor or Nurse for the following handout:

Sun Safety #398

Information about Alcohol and Tobacco use:

- Nicotine is a type of drug that excites body functions (**stimulant**). Stimulants increase alertness, attention, and energy, as well as elevate blood pressure, heart rate, and respiration. Smoking and tobacco products may make IBD become more active.
- Do not smoke around your child or in your home.
- Tell your child that smoking is harmful to patients with IBD.
- Your child should not drink alcohol. Your teen should be aware that it is dangerous to drink alcohol while taking IBD medicines because it is possible to have side effects. Some medicines may contain alcohol. Speak with your GI doctor or pharmacist before giving your child any products with alcohol as an ingredient.

Ongoing care

IBD is a chronic condition needing life-long care. We will help your teenage child learn to manage his or her own health care when transitioning to adulthood. The goal of the GI Team is to help your child become independent, encourage decision-making and teach important health care skills to manage IBD. As your child gets older, the IBD team and your child's GI doctor will work with you and your child to gradually shift care responsibilities from you to your child. These skills will be important as your child transitions from a pediatric setting to an adult GI doctor.

We will assist you with this transition process. In general, this transfer of care will occur around the time of high school graduation or somewhere between his or her 18th to 21st birthday. In most cases, we are able to provide care to your child up until age 21.

Topics that may be addressed during the transition process:

- Transfer of care responsibilities from parent to patient
- Adult health concerns to discuss:
 - work
 - school
 - sexuality
 - cancer awareness
 - health of the bones
- Worries or fears about transferring to an adult PCP
- Choosing an adult GI doctor
- Medical and life insurance
- How to get and refill medicines
- Exercise and fitness
- Use of alcohol and tobacco products

School and Outside Activities

Because IBD is a chronic disease, it is important for you and your child to learn to include caring for your child's disease into his or her life. Your child should be encouraged to live as normal a life and routine as possible. This includes going to school.

It is important to tell teachers, the school nurse, coaches and other caregivers about IBD concerns. They need to be aware of your child's diagnosis. They can help your child with needs that come up while your child is at school.

Tips to help your child when at school:

- Ask the school nurse or school counselor for a Chronic Illness or Health Status form. The form states that your child has a chronic illness and should be excused from school absences due to this illness. Bring the form to your GI provider to complete, and return it to your child's school. This form needs to be completed and returned every school year.
- Get hall passes for unlimited use of the bathroom for the entire school year.

- Get a pass for the nurse's office for medicine and for the nurse to assess your child when IBD symptoms start or will not go away during school hours.
- Make sure your child knows the location of the bathrooms he or she can use at school.
- Talk with your child as needed about what he or she will eat and drink at school each day.
- Talk with your child's physical education (PE) teacher so your child can rest as needed during times of increased symptoms.
- Talk to your child's GI doctor before allowing your child to participate in full contact sports.

It is important to talk with school staff if your child needs to miss school or other activities because of his or her IBD. This may include:

- doctor's appointments
- lab or radiology testing
- procedures
- hospital stays
- illness

School programs such as a 504 Plan provide assistance with studies or tutoring if necessary. Our IBD Team can also work with you to develop a plan for gradually returning to school after many absences.

For long hospital stays, Phoenix Children's Hospital offers One Darn Cool School. This is a hospital-based school with Master's degree teachers who are trained in education. They are certified to teach children with special health needs. Teachers can help with school studies for any grade. If needed, they can communicate with your child's teachers. Our teachers can help to keep your child current with schoolwork, as his or her health allows. Homebound instruction may be needed with special situations for long-term illness. Keep in mind, homebound choices should be considered as a **last resort**.

You may need to start a 504 Plan with your school if your child is going to miss more school days than allowed.

For more information, ask your GI doctor or Nurse for the following handouts:

How to Get the Best Education for Your Child with Special Needs, #843

Psychosocial Needs

IBD, like any chronic health condition, impacts the entire family. Having IBD can be hard at times. We want to help your family with all the aspects of your child's journey with IBD. It can be stressful to cope with a chronic disease and come to frequent office visits. It can be challenging to remember to have your child take all of his or her medicine each day while trying to live a normal life. Your child may experience pain, anxiety, fear, depression, anger, body image changes, and emotions throughout the journey with IBD. These issues are normal for anyone dealing with a chronic illness. Our goal is to support each child and family with strategies to cope with these issues if they occur.

Siblings need to be included in care and updated based on their age. Siblings may have feelings of jealousy, fear, guilt, and anger when a brother or sister has a serious illness. Open, honest communication with the rest of the family will provide needed support and comfort for siblings. This may help ease their fears.

Phoenix Children's Hospital has many resources available to help you and your child. Services include:

- Developmental and Behavioral specialists
- Social Work
- Child Life Specialists
- Community Services
- The Emily Center Family Health Library
- Camp Oasis

The Emily Center Family Health Library is located inside Phoenix Children's Hospital. You can use this library to get health information on your child's health and illness issues. Information from The Emily Center is free of charge.

Now that you've read this:

- Tell your nurse or doctor what resources will be important for your child and how you will access them. (Check when done.)
- Tell your nurse or doctor about additional care necessary to help your child stay healthy. (Check when done.)

- Tell your nurse or doctor about the importance of eye exams for your child. (Check when done.)
- Tell your nurse or doctor about the importance of immunizations for your child. (Check when done.)
- Tell your nurse or doctor about the importance of protecting your child's skin from the sun. (Check when done.)

11. I can tell you signs my child is getting worse, how I would respond, and who I would call.

Sometimes it is hard to know who to call with different types of concerns. The lists below are provided as a guide to help you know who to call. If you are not sure who to call, you can always call the GI doctor. We want to work with you to provide the best treatment for your child.

Call your Primary Care Physician (PCP), if your child has any of the following signs of acute illness:

- new onset of fever
- fever that does not go away, even without another medical reason
- cough, cold or congestion symptoms
- skin rash
- any other health care concerns that are not associated with IBD.

Call your GI doctor if your child has any of the following IBD signs:

- increased pain in the belly (**abdominal pain**)
- increase in the number or volume of stools
- blood in stools that can be either bright red or black (tarry)
- constipation
- vomiting, especially if bloody
- increase in size (**bloating**) of the belly

- severe headache, especially if your child has been taking steroid medicines recently
- sudden or severe changes in vision
- quick change in weight by five pounds or more (up or down)
- sudden change in the color of your child's skin, eyes, or urine
- a change in your child's energy level
- mouth sores, sores on the skin, or sores in the diaper or genital area
- joint pain
- unusual bleeding or bruising
- when your child has a flare

Now that you've read this:

- Tell your nurse or doctor what problems might occur with IBD. (Check when done.)
- Tell your nurse or doctor what you will do if your child has one of these problems. (Check when done.)
- Tell your nurse or doctor the phone number for your child's Primary Care Physician and when you would call. (Check when done.)
- Tell your nurse or doctor the phone number for your child's PCH GI Clinic and when you would call. (Check when done.)

12. I can tell you about my child's next GI Clinic appointment

Next GI Clinic appointment:

Date and time: _____

Time to arrive: _____

GI Clinic Location (circle one):

- Main (Phoenix)
- East Valley (Mesa)
- North West (Glendale)
- Scottsdale
- South West (Avondale)

Gastroenterologist (GI doctor): _____

Now that you've read this:

Tell your nurse or doctor when and where your child's next GI Clinic appointment is. (Check when done.)



If you have any questions or concerns,
 call your child's doctor or call _____

If you want to know more about child health and illness,
visit our library at The Emily Center at Phoenix Children's Hospital
1919 East Thomas Road
Phoenix, AZ 85016
602-933-1400
866-933-6459
www.phoenixchildrens.org
www.theemilycenter.org
Facebook: [facebook.com/theemilycenter](https://www.facebook.com/theemilycenter)
Twitter: [@emilycenter](https://twitter.com/emilycenter)

Disclaimer

The information provided at this site is intended to be general information, and is provided for educational purposes only. It is not intended to take the place of examination, treatment, or consultation with a physician. Phoenix Children's Hospital urges you to contact your physician with any questions you may have about a medical condition.

June 5, 2018 • In family review
#1856 • Written by Brenda Strom, MSN, RN

Inflammatory Bowel Disease (IBD) Family Handbook

Name of Health Care Provider: _____

Date returned: _____ db

Family Review of Handout

Health care providers: Please teach families with this handout.

Families: Please let us know what you think of this handout.

Would you say this handout is hard to read? Yes No

easy to read? Yes No

Please circle the parts of the handout that were hard to understand.

Would you say this handout is interesting to read? Yes No

Why or why not?

Would you do anything differently after reading
this handout? Yes No

If yes, what?

After reading this handout, do you have any
questions about the subject? Yes No

If yes, what?

Is there anything you don't like about the drawings?

Yes

No

If yes, what?

What changes would you make in this handout to make it better or easier to understand?

Please return your review of this handout to your nurse or doctor or send it to the address below.

The Emily Center
Health Education Specialist
Phoenix Children's Hospital
1919 East Thomas Road
Phoenix, AZ 85016-7710

602-933-1395

Thank you for helping us!