Personal IBD Notebook

This Notebook Belongs To:

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Main Hospital 401-444-4000

GI Doctor ________________________

GI Doctor After Hours: 401-444-4000 -
prompt #4 and ask for the "Pediatric GI fellow on call"

GI Nurse Line : 401-444-5805

Primary Physician_____________________
Telephone # ___________________________
____

Pharmacy Name: ____________________

Pharmacy Phone #____________________

Pharmacy Fax #______________________

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GI Staff

Introduction

You have been told that your child has inflammatory bowel disease (IBD). You may not know anything about IBD and you have a whole lot of questions – why did this happen to your child and what can you do to help your child? The answers to your questions are to learn as much as you can about IBD.
We want you to have the most reliable and up to date information available so we have prepared this guide for you.

- Use this guide to learn about your child's IBD.
- You will not learn everything overnight. Absorb the information at your own pace.
- Use this guide to become actively involved in your child's care.
- Share it with your child when appropriate, family members, and other health care providers so they can help you and your child.

You, your child, and family members will meet many different health care providers who will contribute to your child's plan of care and well being. The time of diagnosis can be confusing and overwhelming. Your GI Team will be here to assist you through all phases of your child's medical care. So who is on this GI Team?

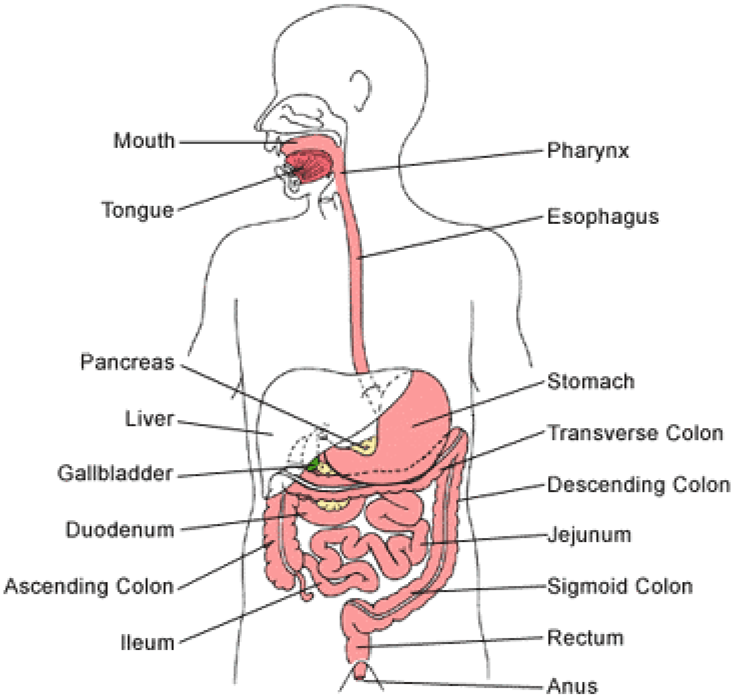
- **GI Doctors/Attending** is a board certified physician in Gastroenterology and pediatrics. He/she will provide education, guidance, and will coordinate the care of you child.
- **GI Fellows** are Board Certified pediatricians, who are receiving further training and education in Gastroenterology; they will become GI Specialists. He/she will provide education, guidance, and will coordinate the care of you child.
- **Registered nurses** are here to provide education for you, your child and family, and to help to coordinate your child's care. The nurses will help guide you through the healthcare system and help you to locate needed resources.
- **Nutritionists/Dietitians** will help to evaluate your child's nutritional state and provide guidance in nutrition to promote optimal health and physical growth.
- **Pediatric psychologists** are available to educate families about the psychological, emotional, and social effects of physical symptoms and illness on children and to assess their emotional and behavioral functioning.
- **Child Life Specialists** are specially trained to work with children who are dealing with their concerns and reactions to hospitalization and illness. They help to promote optimum development in children by reducing stress through preparation and education.
- **Clinical social workers** are licensed professionals trained to help you and your family manage emotional and social problems related to illness and hospitalization.
- **Research staff** will assist you and your child in the participation of programs and studies, of your choice, that will impact future treatments and quality of life for children with IBD in the future.
- **Administration staff** will help you to coordinate clinic visits, hospital stays and help promote communication between you and your child's health care providers.

You are not in this alone. We as your medical team are here to support you and your family. We want to answer your questions. We want to work with you to provide the very best care for your child so that you can help your child lead a full life. Remember, you are your child’s best advocate.

More information on your GI staff members can be found at the rear of the binder

What is the GI (gastrointestinal) Tract?

The GI tract is a pathway made up of parts of the body that work together to turn food and liquids into the fuel that the body needs for energy and growth.



The GI tract starts at the mouth and ends at the anus (opening where the stool comes out). The food that we eat moves through the GI tract by peristalsis (a movement like an ocean wave). After you swallow food moves from the mouth into the esophagus (food tube) then into the stomach. In the stomach food starts to get broken down (digested). What is in the stomach then empties into the small intestine. The parts of the digested food (carbohydrates, fats, proteins, vitamins, water, and minerals) that the body needs are absorbed (passed) through the wall of the small intestine.

The parts of the small intestine are:

Duodenum (first part)
Jejunum (middle part)
Ileum (end that leads into the large intestine)

What the body doesn't need (the waste) passes into the large intestine (colon). In the colon extra water is removed and poop is formed. This takes a day or two. Poop passes into the rectum and then leaves the body through the anus in a bowel movement. Stool can be hard or soft (formed) or loose or liquid. The color of the stool may vary with the different foods that are eaten and if you are sick.

What is IBD (Inflammatory Bowel Disease)?

IBD is a general name for chronic diseases that cause inflammation in the GI tract. The inflammation is in the mucosa or the inner lining of the GI tract. The mucosa protects the body on the inside like the skin protects it on the outside. The two most common types of IBD are Crohn's disease and ulcerative colitis.

What does inflammation mean?

A word ending in "itis" means inflammation. Inflammation can happen anywhere in the body. The first part of the word tells the body part that is inflamed. For example:

appendicitis is inflammation of the appendix

Inflammation is how your body reacts to:

- an infection (germs or the bacteria)
- tissue injury (damage from cells)
- foreign body (toxins)
- chemicals (which can be released from sick or damaged cells)

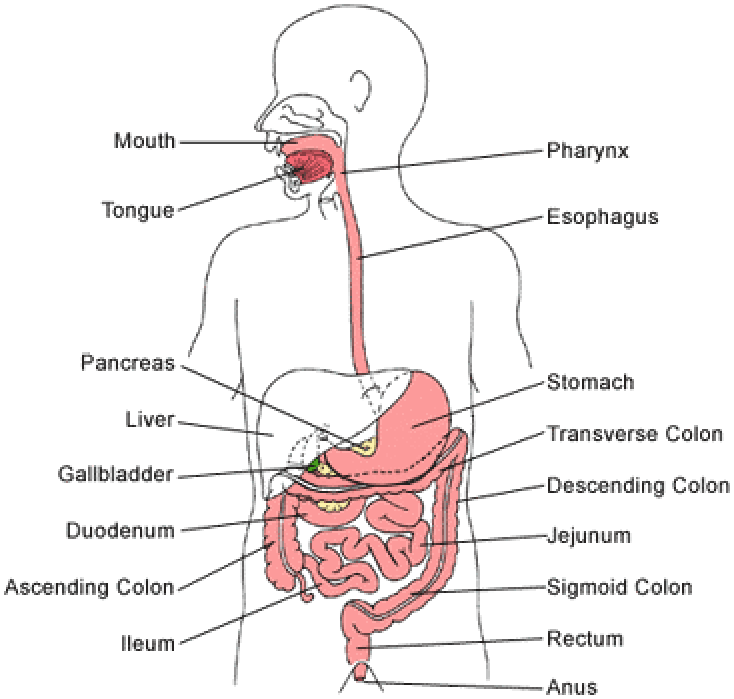
Inflammation in the intestine makes the mucosa red, swollen and sores called ulcers develop. The ulcers damage the mucosa. You can get diarrhea, bleeding, and abdominal pain. The inflammation also blocks the absorption of nutrients from food.

What is Crohn's Disease?

Crohn's disease is inflammation which can affect any part of the GI tract (mouth, esophagus, stomach, small or large intestine, and the skin outside the anal opening). The diseased parts are mixed in with normal healthy areas called skip areas. The inflammation in Crohn's disease is deep within the intestinal wall. It affects all of the layers of the intestine. The symptoms of Crohn's disease can be different for each person. Some of the common symptoms are:

- abdominal pain
- diarrhea (with or without blood)
- fevers
- fatigue (feeling tired)
- poor appetite
- poor growth
- perianal disease (diseased areas near the anal opening)

The kinds of symptoms your child may have depends on where the disease is located. Your child's disease is located:

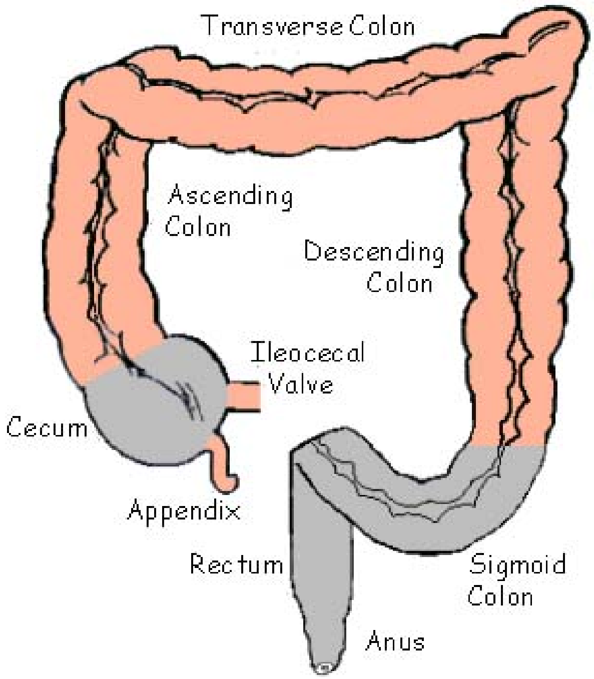


What is Ulcerative Colitis?

Ulcerative colitis is inflammation which affects only the large intestine or colon (colitis). The inflammation usually starts in the rectum and goes upward through the entire colon. There are no skip areas and the inflammation does not affect the entire intestinal wall as in Crohn's disease. Common symptoms of ulcerative colitis are:

- abdominal pain,
- bloody diarrhea (which can be frequent and in large amounts)
- tenesmus (urgency to stool)
- fatigue (feeling tired)
- weight loss
- poor appetite

The severity of the symptoms are related to the severity of the inflammation. In other words the more inflammation the worse
the symptoms may be. Your child's disease is located:



Crohn's disease and Ulcerative colitis are similar illnesses with similar symptoms. In a small group of patients (10%) doctors cannot be positive about the diagnosis, These patients are diagnosed with indeterminant colitis.

What does having a chronic illness mean?

Crohn’s disease and ulcerative colitis are chronic illnesses. A chronic illness means that the illness can’t be cured, but it can be treated and controlled. At times the illness may be active with symptoms called a flare or exacerbation. At other times the illness is not active called a remission.

Do children have the same symptoms as adults?

Children often have different symptoms than adults. Before a diagnosis was made your child may have had some of the more common GI symptoms, but this is not always the case. Very often children are tired, have fevers without having an infection, complain of joint pains, and have poor appetites which may have led to poor growth. The poor growth may have affected your child’s height (linear growth) and the development of puberty. Vague symptoms that start before GI symptoms make it difficult to diagnosis IBD in children.

Who Gets IBD?

Approximately 1 million Americans have IBD and the number is on the rise. Males and females are equally affected by IBD. IBD occurs in all populations but it is more common in Caucasians living in the developed western countries. It is also more common in the European and North American Jewish population.

Why did my child get IBD?

It is known that IBD tends to run in families. If you have a relative with Crohn’s disease or ulcerative colitis your chances of developing IBD are 10 times greater than the general population. If you have a brother or sister with Crohn’s disease or ulcerative colitis your chances of developing IBD are 30 times greater than the general population.

IBD can occur at any age. It is usually diagnosed in the late teens and twenties and between the ages of 55-65. It is estimated that 100,000 people with IBD are under the age of 18 and many of them are diagnosed before the age of 20. It is one of the most important chronic diseases to affect children and adolescents.

How will IBD affect my child's daily life?

Having a child with a chronic illness impacts the entire family. When your child is well there is little effect on day to day activities. When your child is having a flare there may be disruptions in family life, social activities, and school attendance. Studies have shown that children with IBD lead normal
productive lives.

Children with IBD can also experience a variety of concerns and perceptions about their life with IBD. Studies have shown that age appropriate open family communication is helpful and supportive to the child with IBD. These issues are discussed in more detail in the Psychosocial Issues in Children and Adolescents with IBD section

What causes IBD?

No one knows what causes IBD. Scientists do know that IBD is **not** caused by emotional distress or sensitivity to foods and it is not contagious. The most researched idea involves three circumstances. First, a person must be genetically susceptible to IBD (you have inherited the gene or genes which allow you to develop IBD). Second, something in the environment such as a bacteria or a virus starts the immune response. Lastly, the immune system responds incorrectly.

How does the immune system work?

The immune system works at preventing harmful or dangerous materials such as bacteria and viruses from entering your body. If a harmful material does enter your body then the immune system's job is to attack and destroy that material. This is called the "immune response". Many parts of the body play a role in the immune response. The intestine is part of this response. In the person with a normal functioning immune system, immune cells attack and destroy the harmful material and then the immune system returns to normal. In the person with IBD the immune response does not go back to normal. It continues to attack. The attack then damages the mucosa causing the symptoms of IBD.

HOW WILL YOUR DOCTOR DIAGNOSE IBD?

There is no single test to diagnose IBD. Once your child has been referred to a gastroenterologist (GI doctor) a complete history and physical will be performed. The doctor will ask questions about your child's recent and past health, family history, and how your child is generally feeling. It is important to answer the questions as precisely as possible.

The doctor will perform a physical. Special attention is paid to the abdominal and the rectal area. He or she will probably do a rectal exam and test your child's stool for hidden blood.

The doctor will assess your child's growth and development using the standardized growth charts. A bone age Xray may be ordered to determine the potential for growth.

Blood tests will be ordered to look for infection, anemia, inflammation, and the nutritional state of your child.

Stool tests will be ordered to rule out a bacterial or parasitic infection which can imitate the symptoms of IBD.

An upper endoscopy (EGD) will be ordered to look at the esophagus, stomach, and the beginning part of the small intestine.

A colonoscopy will be ordered to look at the large intestine. The EGD and colonoscopy are performed at a later time while your child is asleep under general anesthesia. Small pieces of tissue called biopsies are taken at the time of procedure. The pieces of tissue are examined under a microscope. A different physician called a pathologist looks for certain cells that tell if your child has Crohn's disease or ulcerative colitis.

The doctor will order a barium X-ray test called an upper GI with a small bowel follow through to see the middle part of the small intestine. After an overnight fast your child will swallow flavored barium and then X-rays are taken as the barium travels through the GI tract.

The doctor will review all of the test results and discuss them with you.

DOES IBD CAUSE PROBLEMS ONLY IN THE GI TRACT?

No, IBD can cause problems outside of the GI tract. It can affect the joints, skin, eyes, and the liver. These are called extraintestinal manifestations. Many children (25-35%) with IBD experience one or more of the extraintestinal manifestations.

Because children do not always experience the more common GI symptoms, it is important to be aware of problems in other areas of the body. **Any symptoms of extraintestinal manifestations may be a clue as to how active your child's disease might be.** The extraintestinal symptoms will get better as the IBD symptoms get better.

The most common joint problem is **arthritis**. The hips, knees, shoulders, wrists, ankles, elbows, and back are the most often involved. The GI doctor may refer your child to a rheumatologist. We do not usually recommend non steroidal anti inflammatory (NSAID's) such as ibuprofen because they may cause a flair of IBD symptoms, but they are sometimes necessary especially for joint symptoms. Acetaminophen (Tylenol) may be used for pain control. Non-weight bearing exercise and or physical therapy may also be helpful

Skin problems occur in some people (15%) with IBD. The two most common problems are rashes called erythema nodosum and pyoderma gangrenosum. Either rash may appear when the disease is active. **Erythema nodosum** is an acute inflammation of the fat just under the skin. You can have fever and generally not feel well (malaise). Large, red, painful areas appear on the lower legs. The doctor can feel the bumps underneath the skin.

Pyoderma gangrenosum happens suddenly. Painful open areas (ulcers) can appear on the legs, buttocks, abdomen or the face. The ulcers are surrounded by puss. The GI doctor may refer your child to a dermatologist.

An ulcer in the mouth called an aphthous ulcer may appear if IBD is active. An **aphthous ulcer** is much like a chancre sore and can be quite painful. They can appear alone or in groups. The doctor may prescribe a topical anesthetic and a special mouthwash.

Some people (10%) have eye problems. **Uveitis** is an inflammation in the middle layer of the eye wall. It can cause eye pain, blurry vision, redness of the eye, and sensitivity to light. Uveitis gets better with treatment of the IBD. Your eye doctor may prescribe eye drops.

Episcleritis is an inflammation of the outer coating of the white of the eye. The blood vessels get large and the eye looks red. Your eye doctor may prescribe eye drops.

Problems with the liver and the biliary system can happen in IBD, but it is rare.

Primary sclerosing cholangitis (PSC) is an inflammation that causes scarring in the bile ducts. The bile ducts transport bile from the liver to the small intestine for digestion. The classic symptom of PSC is itching which is worse in the warm weather and at night.

Notify the GI doctor if your child complains of:

- swollen, painful or stiff joints
- blurry vision, eye pain or sensitivity to light
- skin rash, mouth sores or itching

IMPORTANT THINGS TO REMEMBER

Your child should be up to date on vaccinations (immunizations).

If your child is taking steroids:

> Your child should not receive any live virus immunizations. Your child must be off steroids for at least 3 months before receiving any live virus vaccines.

The live virus vaccines are:

- **Oral polio** (OPV)
- **Measles, Mumps, Rubella** (MMR)
- **Flu Mist Nasal Spray**
- **Chicken pox** (Varivax)

Your child **can** have the inactivated polio vaccine (**eIPV)** if they are on steroids.

Household members living with the child who is on steroids **shouldn't** receive the oral polio vaccine.

If your child is on steroids and or 6 MP notify physician immediately if your child has been exposed to chicken pox **and** has never had chicken pox **or** has never had the varicella vaccine (chicken pox vaccine).

Your child **should** receive a yearly flu shot.

Your child should have a yearly eye examination by an ophthalmologist.

Your child will need a yearly tuberculin (TB) skin test.

Immunizations for Children & Teens with IBD

1. We recommend all standard vaccinations when possible

2. We recommend the flu vaccine in season
   Illnesses such as influenza can trigger a flare up of Crohn's disease or Ulcerative Colitis so preventing the illness may prevent a flare up

3. Children receiving 6MP / 6 mercaptopurine/ Purethinol or AZA/ azathioprine/ Imuran, should NOT receive live virus vaccines.

4. A person is not likely to benefit much from getting a vaccine while taking high doses of Prednisone. The Prednisone prevents the immune system from learning to recognize the vaccine well. Wait to give the vaccine at a time when the Prednisone has been tapered down or ended.

5. A person may have a decreased response to a vaccine received while on low dose Prednisone and 6 MP or AZA, but overall, people will still have benefit from these vaccinations.
   Consideration will be made for an increased dose of Hepatitis B Virus (HBV) immunization on teenagers or for a four dose schedule for children & teenagers on 6 MP or on AZA/ Immuran.

6. The standard precautions for giving vaccinations still apply. A person should not receive a vaccination during moderate or severe illness or if they have previously had a severe reaction to a vaccination.

Live U.S.Vaccines (per CDC)

Vaccine	Trade Name	Abbreviation	Type	Route	Comments
Herpes Zoster (shingles)	Zostavax	ZOS	Live viral	SC	licensed for age 60 and older
Influenza	FluMist	LAIV	Live attenuated viral	Intra-nasal	Trivalent types A & B Minimum age = 18
MMR	M-M-R II	MMR	Live attenuated viral	SC	Measles, mumps, rubella
MMRV	ProQuad	MMRV	Live attenuated viral	SC	Measles, mumps, rubella, varicella
Rotavirus	RotaTeq	RV5	Live viral	Oral	Pentavalent. First dose between 6 weeks & 14 weeks 6 days; complete 3-dose series by 8 months 0 days
	Rotarix	RV1	Live viral	Oral	Monovalent. First dose between 6 weeks & 14 weeks 6 days; complete 2-dose series by 8 months 0 days
Typhoid	Vivotif		Live bacterial	Oral	Ty21a strain
Varicella	Varivax	VAR	Live viral	SC	
Vaccinia (Smallpox)	ACAM2000		Live viral	Percutaneous	

What should I expect when visiting the doctor?

Visiting the doctor is a time to exchange information and to ask questions. The doctor will ask you for information about your child. Try to answer the questions fully as this helps provide the best care for your child.

You may want to ask questions of the physician. It is helpful to have your questions prepared in advance of the visit.

Your child will have his or her weight, height, and vital signs checked at each doctor's visit. You will be asked what medications your child is taking, if there are any allergies, and generally how your child has been feeling since the last visit.

Your doctor needs to know all of the medicines and the amounts that your child is taking. This includes over the counter medicines. It may be helpful to bring all of the medicines with you to make sure you give the doctor the right information.

Your doctor will discuss your child's progress, his/her growth and how it relates to the standardized growth charts. The growth charts are used for monitoring appropriate physical development and for detecting growth delay.
The physician will also address any concerns that you may have.

Finally, the doctor will discuss the plan of care for your child. You and the physician should agree on that plan of care. You will be given specific guidelines of what to do in certain situations and what to do if the plan is not working.

Make sure all of your concerns or questions have been addressed. Make sure that you understand any instructions given. Remember that no question is stupid and if you are unclear about something speak up.

When Should I Call My GI Team ?

It is expected that there will be times you will have to call your GI Team. You should discuss when and how to reach someone with your GI Team so that you know what to do when the time comes.
Specifically, you should ask your team the following questions:

- ***For what type of problems would you like me to call?***

- ***What number do I call during usual business hours?***
  Nurse line # 401-444-5805

- ***What number do I call after business hours and on weekends?***
  401-444-4000 option #2 and ask for the Pediatric GI Fellow on call

- ***Who should I call for non-urgent problems such as lab results, prescription refills or school notes?***
  401-444-8306 and choose the appropriate prompt

- ***How long does it usually take to get a call back?***
  Phone calls are prioritized in the order of urgency
  and are returned as quickly as possible

Nurse Line:
401-444-5805
Information to leave: Name of patient, date of birth, phone number where you are easily contacted & problem to be addressed

In some practices, secretaries or nurses may handle non-urgent calls.
If you feel that you must speak with the physician on the team, you should make that clear when you leave your original message, so that multiple people do not have to call you back.

> Emergency or urgent calls deal with problems that need to be addressed more quickly. If you believe you are having an emergency or urgent problem, you should make the team aware of this from the start. If you are having an emergency and cannot reach a member of your GI Team or the GI Fellow on call, you may need to be seen by your primary doctor or in an Emergency Room.

When you call your GI Team about your health, you should think about symptoms in terms of how they have changed for you. It is helpful for your GI Team to know:

- how long you have had symptoms
- if they are worsening, or changing in any way.
- You should become aware of what your “baseline” health is and know when it changes.
- Please make sure that you have asked your child about the symptoms
  If there is a privacy issue then maybe your child should speak to us as well

The bigger the change, the more urgent your phone call becomes; learn to listen to your body!

HOW WILL I KNOW WHEN TO CALL THE DOCTOR?

We would like you to call the doctor or the nurse when you have a question or if you think that your child is having symptoms of a flare up. When you call in the nurse or the doctor will need certain information. The more precise you are the easier it is to help you over the telephone. Here are some of the questions the nurse or the doctor will ask:

If your child is having abdominal pain:

- Where is the pain?
- What kind of pain? Is it crampy, sharp, dull?
- How long does it last?
- When does the pain occur?
- If possible have your child rate the pain on the pain scale from 1-10

If your child is having diarrhea:

- Is the stool loose, watery, does it look like mucus?
- How many stools in a 24 hour period?
- Is it a large amount?
- Is there blood in the stool?

Does your child have a fever?

- Take the temperature with a thermometer

If your child vomiting:

- How often and how much is your child vomiting?
- Is your child able to keep any liquids down?
- What does the vomit look like?

Is your child more tired than usual?

- Is your child doing their usual daily activities (going to school, extra activities)?

Describe your child's appetite?

What medications is your child taking?

Does your child have any other complaints such as joint pains, mouth sores

Medications Used to Treat IBD

Medications are used to relieve the symptoms of IBD and to keep your child in remission. Many of the same medicines are used for both Crohn's disease and ulcerative colitis. The medications or combinations of medications will be chosen individually for each child. The following list does not include all of the possible medications, but it does include the most frequently used medicines in children.

Aminosalicylates (5-ASA)

- Most frequently prescribed group of medications for the treatment of IBD in children.
- 1st line of therapy for both achieving and maintaining remission.
- Similar to aspirin.
- Decrease inflammation in the intestine and to keep your child in remission.
- Released in the inflamed area of the intestine.

More frequently used aminosalicylates are:

Pentasa

- Capsule containing granules which are slowly released in the small and the large intestine.
- The capsule should be swallowed whole, but it can be opened and the granules mixed with fruit, pudding or ice cream, if your child cannot swallow the capsule.
- Comes in 250 mg and 500 mg capsules, usually given two or three times a day.

Asacol

- Enteric coated tablet which is released in the terminal ileum and the large intestine.
- Tablet should not be cut.
- Asacol comes in 400 mg and 800 mg tablets given two or three times a day.

Rowasa enema

- Rectal preparation which delivers the medicine to the left colon only.
- Comes in 1 gram (60 ml or 2 ounces) and 4 gram (100ml or 3 ounces) sizes.
- In pediatrics the 1 gram size is used given once or twice a day.

The most common side effects of this group of medications are:

- Diarrhea
- Headache
- Nausea

Rare side effects that have been reported are:

- hair loss
- kidney stones
- pancreatitis

Corticosteroids

- Prednisone is a medication called a corticosteroid.
- It is very much like the hormones or steroids which are produced daily by the adrenal glands in your body.
- Corticosteroids affect every cell in the body and are necessary in very small amounts for normal body function.
- When your body is under physical stress steroid production is increased as one of the body's protective responses.

Prednisone works by reducing inflammation in the body. It is used to treat some conditions which are caused by inflammation such as asthma, skin and joint diseases, and inflammatory bowel disease. In inflammatory bowel disease as inflammation is reduced in the intestine, many of the symptoms will improve.

- Work to reduce inflammation and to suppress the immune system.
- Used for acute exacerbations (flare ups) of IBD.
- They are not the same as "body-building steroids"

- **Prednisone, prednisolone, orapred**
  These are the most common drugs used in this group of medications.
  As your child's IBD symptoms improve your physician will start to decrease (taper) the prednisone with the goal of discontinuing the medicine altogether. Our goal is to have your child on prednisone for the shortest amount of time necessary.

- **Solumedrol**
  A form of Prednisone is usually given intravenously while your child is in the hospital. At home your child will take this medicine either in pill or liquid form. You will be given specific instructions when and how to take the prednisone.

- **Anusol – HC**
  A topical steroid cream used for perianal disease.

- **Hydrocortisone enema**
  A rectal preparation used for active disease in the rectum and the left side of the colon.

Side Effects

- **To be reported to your doctor immediately:**
  - Decreased or blurry vision
  - Frequent urination
  - Increased thirst
  - Bloody stools
  - Bone pain

Common but possible and reversible side effects of taking steroids are:

- **Weight gain**
    - Especially visible in the face called (moon face or cushinoid).
    - Some weight gain is water (fluid) weight because prednisone makes your body hold onto salt and water.
    - It is also from an increase in appetite because prednisone stimulates your appetite – a lot!

- **Increased Appetite**
    - Try to eat small frequent meals
    - Make healthy food choices
    - Avoid excess salt and salty foods like chips, french fries, etc.

- **Hypertension** (an increase in blood pressure)
    - a result of extra fluid.

- **Acne**
    - Caused by hormonal changes from the medicine.
    - Encourage your child to practice good skin hygiene and to make healthy food choices.
    - If the acne is particularly bad then your GI doctor may refer your child to a dermatologist.

- **Insomnia** or a disturbance in your child's sleep pattern
    - It may be helpful to establish a routine for bedtime and to learn some relaxation techniques.

- **Mood swings**
    - Obvious and unpredictable while your child is on prednisone.
    - Your child may feel happy one minute and sad the next.
    - If you think your child is depressed or if you feel overwhelmed your child may benefit from seeing one of our psychologists.

- **Hair growth** on the face may be visible while on prednisone.

- **Striae** (stretch marks)

    - Caused by stretching of the skin and hormonal changes.
    - Over the counter creams specially made for stretch marks may be helpful.
    - Striae don't usually disappear but they fade over time.

- **When to tell your doctor that you are on prednisone:**
  - Before any immunization or skin test
  - Before having surgery or emergency treatment
  - If you have any serious infection
  - If you become pregnant
  - Before you have any dental work

- DOCTOR MAY ALSO RECOMMEND:
  - **Bone density x-rays to evaluate any thinning (demineralization) of the bones.**
    Nutritional therapy may counteract the effect of bone demineralization
  - **Ophthalmology consult will address any eye problems such as cataracts**
  - These two possible side effects may not be reversible

Remember:

- As a parent it is worrisome to read the list of possible side effects.
- They are reversible.
- They will gradually disappear as the medication is weaned down.
- Some children are upset by the physical changes in their appearance.
- Reassure your child that these changes will eventually go away as the medicine is weaned.

The physical changes can be overwhelming to adolescents. Adolescents are struggling with their body image and the need to fit in with their peer groups. Limitations from a chronic disease can have a significant impact on social development and school. It is important for the parent to provide ongoing reassurance that the obvious cosmetic changes will eventually improve.

It is not unusual for an adolescent to decide to stop taking their medications. Making sure that your child is taking all of their medication is important. Encourage your child to express any thoughts about their illness and the treatment. Let medical professionals know about any medication issues. We will work closely with you and your child to help resolve the situation.

Please keep in touch with your GI physician or nurse and report any complaints that your child may have. If your child has a complaint and you are not sure if it is important then please ask.

Remember: No question is a stupid question

Antibiotics are often prescribed for children with IBD. They affect the immune system and help to decrease bacteria in the intestine.

- **Metronidazole (flagyl)**
  - Used to treat the fistulas and abscesses which can develop in Crohn's disease.
  - They come in 250 mg and 500mg tablets and can also be made into a suspension.
  - Possible side effects are:
- Metallic taste in mouth
- Nausea
- Vomiting
- Headache
- dark urine
- numbness/tingling in hands and feet
- anorexia (loss of appetite)
- Metronidazole affects the way your body breaks down alcohol. Do not drink alcohol while on metronidazole because it may result in severe nausea and vomiting.

- **Ciprofloxacin** is called **cipro**.
  - Used to treat perianal disease in Crohn's.
  - Cipro comes in 250 mg and 500 mg tablets.
  - Possible side effects are:
  - Nausea
  - Diarrhea
  - Abdominal pain
  - Rash

Additional Information

- Take cipro at a different time than antacids or vitamins containing calcium, iron, and zinc.
- Stay out of the sun while taking cipro.

Immunomodulators are a group of medications which suppress the immune system. They are used to keep your child in remission and to help in weaning and staying off steroids.

- Take as long as 3-6 months before they start to work.
- Started while your child is on steroids with the goal that by the time your child has weaned off the steroids this medicine will have taken effect.

- **Azothiaprine (imuran)**

  - Comes in 50, 75 & 100 mg tablets. The tablet can be cut & can also be made into a suspension.
  - Possible side effects
    - GI Upset – give with food
    - Hair loss
    - Liver problems

- **6 MP (mercaptopurine) or purinethal**

  - Come in 50 mg tablets. The tablet can be cut & can also be made into a suspension.
  - Possible side effects are:
  - Liver problems
  - Pancreatitis
  - Depressed blood cell production
- **Methotrexate**
  - Given as an injection once every week
  - Can be changed to oral after a period of time depending on how your child is progressing
  - Comes in tablets 2.5 & 10 mg and also comes in a liquid
  - Your child will need to take folic acid while on this medication
  - Possible side effects
    - Nausea, vomiting & diarrhea

Blood work is checked frequently to monitor for liver, pancreatic, and blood cell problems.
If your child has nausea or vomiting please report this to physician or nurse immediately.

Biologics are a group of new medications that interfere with the body's inflammatory response and suppress the immune system. They are used to treat fistulas and severe IBD which has not responded to other medications.

- **Infliximab (Remicade)** is available as an IV infusion.
    - Series of three infusions are given to start.
    - Second dose is given 2 weeks after the first,
    - Third dose is given 4 weeks after the second.
    - The infusion is given in our outpatient infusion area and it takes about 4 hours
    - Vital signs are monitored throughout the treatment.
    - Possible reactions during an infusion are:
        - Headache
        - Fever
        - Chills
        - Low blood pressure
- **Adalimumab (Humira)** is available as a subcutaneous injection
    - Dosage is based on the child's weight
    - 1st or 2nd doses may be larger than the maintenance dose
    - 1st dose is given at the doctor's office
    - Subsequent doses are given in the home after training is completed
    - Possible side effects are:
        - Pain & redness at the injection site
        - Itching at the injection site
        - Headache
        - Nausea
        - Upper respiratory infection
        - Rash

Medications or a change in the infusion rate usually relieve the common reactions. Your child must have a yearly TB (tuberculin) skin test because remicade has the potential ability to activate a latent (inactive) tuberculosis infection.

Safe Handling of Medications

With all medications:

Good hand washing is a must both before and after giving the medication
Gloves should be worn
Keep all medications, utensils, gloves and masks in designated location

Specific Medications:

- **6 MP**
    - If breaking or cutting a tablet, mask should be worn to avoid inhaling
    - Careful disposal of the "crumbs/dust" which results from the cutting
- **Humira**
    - Refrigerate
    - Disposal of the syringe in a needle container
- **Methotrexate**
    - Mask should be worn to avoid inhaling
    - Avoid contact with skin or eyes – may cause irritation
    - Keep out of direct light

Medication therapy is an important part your child’s treatment for IBD.
The medicines that have been discussed are the most up to date and the most often used in children in our GI practice,
but they are not the only medicines available.
The combination of medicines are specially chosen for your child as an individual.
New medicines are constantly being developed and tested.

List of Common IBD Medications (By Generic)

Generic Name	***Trade Name***	***Foreign Name***	***Dosage Forms***	***Medication Class***
Azathioprine	Imuran		Tablet (50 mg)	Immunomodulator
Balsalazide	Colazal		Capsule (750 mg)	5-ASA
Budesonide	Entocort EC		Capsule (3mg)	Corticosteroid
Ciprofloxacin	Cipro		Capsule (250 mg)	Antibiotic
Cyclosporine	Neoral		Capsule (25, 100 mg), Liquid (100 mg/ml)	Immunomodulator
Hydrocortisone	Anusol-HC Ointment		Ointment (1%, 2.5%)	Corticosteroid
Hydrocortisone	Anusol-HC Suppository		Suppository (25 mg)	Corticosteroid
Hydrocortisone	Cortenema		Enema (100 mg/60 ml)	Corticosteroid
Hydrocortisone	Cortifoam		Rectal Foam (10%)	Corticosteroid
Hydrocortisone	Proctofoam-HC		Rectal Foam (1%)	Corticosteroid
Infliximab	Remicade		Injection (100 mg)	Biologic Agent
Lansoprazole	Prevacid		Capsule (15, 30 mg), Liquid (1 mg/ml)	Acid Blocker
Mercaptopurine	Purinethol		Tablet (50 mg)	Immunomodulator
Mesalamine	Asacol		Tablet (400 mg)	5-ASA
Mesalamine	Canasa		Suppository (500 mg)	5-ASA
Mesalamine	Pentasa		Capsule (250 mg)	5-ASA
Mesalamine	Rowasa		Enema (1 gram)	5-ASA
Methotrexate	Folex		Tablet (2.5 mg), Injection (25 mg/ml)	Immunomodulator
Methotrexate	Mexate		Tablet (2.5 mg), Injection (25 mg/ml)	Immunomodulator
Methotrexate	Rheumatrex		Tablet (2.5 mg), Injection (25 mg/ml)	Immunomodulator
Methylprednisolone	Medrol		Tablet (2,4,8,16,32 mg)	Corticosteroid
Metronidazole	Flagyl		Tablet (250 mg)	Antibiotic
Olsalazine	Dipentum		Tablet (250 mg)	5-ASA
Omeprazole	Prilosec		Capsule (10, 20 mg)	Acid Blocker
Prednisolone	Pediapred		Liquid (5 mg/5 ml)	Corticosteroid
Prednisolone	Prelone		Liquid (15 mg/5 ml)	Corticosteroid
Prednisone	Deltasone		Tablet (2.5,5,10,20 mg)	Corticosteroid
Ranitidine	Zantac		Tablet (150 mg), Liquid (15 mg/ml)	Acid Blocker
Sulfasalazine	Azulfidine	Salazopyrin	Tablet (500 mg)	5-ASA

List of Common IBD Medications (By Medication Class)

Medication Class	*Trade Name*	*Generic Name*	*Foreign Name*	*Dosage Forms*
5-ASA	Asacol	Mesalamine		Tablet (400 mg)
5-ASA	Azulfidine	Sulfasalazine	Salazopyrin	Tablet (500 mg)
5-ASA	Canasa	Mesalamine		Suppository (500 mg)
5-ASA	Colazal	Balsalazide		Capsule (750 mg)
5-ASA	Dipentum	Olsalazine		Tablet (250 mg)
5-ASA	Pentasa	Mesalamine		Capsule (250 mg)
5-ASA	Rowasa	Mesalamine		Enema (1 gram)
Acid Blocker	Prevacid	Lansoprazole		Capsule (15, 30 mg), Liquid (1 mg/ml)
Acid Blocker	Prilosec	Omeprazole		Capsule (10, 20 mg)
Acid Blocker	Zantac	Ranitidine		Tablet (150 mg), Liquid (15 mg/ml)
Antibiotic	Cipro	Ciprofloxacin		Capsule (250 mg)
Antibiotic	Flagyl	Metronidazole		Tablet (250 mg)
Biologic Agent	Remicade	Infliximab		Injection (100 mg)
Corticosteroid	Anusol-HC Ointment	Hydrocortisone		Ointment (1%, 2.5%)
Corticosteroid	Anusol-HC Suppository	Hydrocortisone		Suppository (25 mg)
Corticosteroid	Cortenema	Hydrocortisone		Enema (100 mg/60 ml)
Corticosteroid	Cortifoam	Hydrocortisone		Rectal Foam (10%)
Corticosteroid	Deltasone	Prednisone		Tablet (2.5, 5, 10, 20 mg)
Corticosteroid	Entocort EC	Budesonide		Capsule (3mg)
Corticosteroid	Medrol	Methylprednisolone		Tablet (2,4,8,16,32 mg)
Corticosteroid	Pediapred	Prednisolone		Liquid (5 mg/5 ml)
Corticosteroid	Prelone	Prednisolone		Liquid (15 mg/5 ml)
Corticosteroid	Proctofoam-HC	Hydrocortisone		Rectal Foam (1%)
Immunomodulator	Folex	Methotrexate		Tablet (2.5 mg), Injection (25 mg/ml)
Immunomodulator	Imuran	Azathioprine		Tablet (50 mg)
Immunomodulator	Mexate	Methotrexate		Tablet (2.5 mg), Injection (25 mg/ml)
Immunomodulator	Neoral	Cyclosporine		Capsule (25, 100 mg), Liquid (100 mg/ml)
Immunomodulator	Purinethol	Mercaptopurine		Tablet (50 mg)
Immunomodulator	Rheumatrex	Methotrexate		Tablet (2.5 mg), Injection (25 mg/ml)

Founded in 1973, the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) is the professional organization of 1000 specially trained physicians expert in inflammatory bowel disease and other disorders of the gastrointestinal tract, liver and nutrition. The mission of NASPGHAN (pronounced nás-pa-gan) is to be a world leader in advancing the science and clinical practice of pediatric gastroenterology, hepatology and nutrition in health and disease. NASPGHAN is committed to improving the health and well being of children and adolescents with Crohn's Disease and Ulcerative Colitis, which are also called inflammatory bowel disease (or IBD for short). NASPGHAN has an Inflammatory Bowel Disease Committee, a Professional Education Committee and a Public Education Committee. Through these committees, the physician members of NASPGHAN work to improve the medical care of children with IBD. They are writing a book for parents whose children have IBD, writing clinical guidelines to guide physicians in the best care of children with IBD, improving research in pediatric IBD, as well as developing, producing and distributing this NASPGHAN Personal IBD Notebook. See *http://www.naspghan.org*.

Founded in 1998 by NASPGHAN, the Children's Digestive Health and Nutrition Foundation (CDHNF) was established to promote and develop funds for research and education to improve the health of children with digestive and nutritional disorders. The mission of the Children's Digestive Health and Nutrition Foundation is to fund and promote research and educational programs that will advance the creation, application, and dissemination of knowledge of gastrointestinal, hepatobiliary, pancreatic and nutritional disorders in children, including Crohn's Disease and Ulcerative Colitis; to identify, encourage, support, and coordinate scientific and professional study of these pediatric disorders; to strengthen the role of pediatric gastrointestinal and nutritional scientists as leaders in research and education in these medical and health care fields; to evaluate and improve the quality and availability of medical care for children with digestive disorders; and to support the research and educational programs of NASPGHAN. See *http://www.cdhnf.org*.

The formation and ongoing purpose of The Association of Pediatric Gastroenterology and Nutrition Nurses (APGNN) is to promote the professional development and recognition of pediatric nurses as experts in their field; and to promote excellence in the care of families with children with gastrointestinal and nutritional illness. Nurses in APGNN are specially trained and experienced in the care of children and adolescents with Crohn's Disease and Ulcerative Colitis. See *http://www.naspghan.org/sub/apgnn.asp*.

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Helpful Websites

Pediatric Gastroenterology, Nutrition and Liver Diseases – Hasbro Children's Hospital
http://www.lifespan.org/hch/services/gi/
Find information about your Pedi GI team members, the programs offered, links to the IBD Support Group and it's newsletter *The Gastro Gossip*, as well information about on-going important research projects.

North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition
www.naspghan.org
This webiste provides links under "Family Resources" about disease specific information. Download ***"Your Personal NASPGHAN IBD Notebook,"*** as a helpful tool in managing your IBD - a great way to "store vital information about your child's disease, such as the details about diagnosis, medications, lab reports, and procedures."

The Crohn's and Colitis Foundation of America
www.ccfa.org
Offers links to information about: "Living with IBD," as well as disease specific information and a special section for kids and teens. The following educational brochures are available for downloading: Living With Crohn's Disease; Living With Ulcerative Colitis; A Guide for Kids and Teenagers; Pete Learns All About Crohn's & Colitis (an educational comic book for school age children and teens); A Guide for Parents; A Guide for Teachers and Other School Personnel; Diet and Nutrition; Emotional Factors.

Site for Kids:

UC and Crohns.org
www.ucandcrohns.org
"This site features teens talking about living with colitis and Crohn's. They share their stories and tips -- and you can even share your own! The site also has chats, fun quizzes and surveys, and places where you can get more information tailored just for you."

IBD U - Graduating to Independence
www.ibdu.org
From Starlight and the Children's Digestive Health & Nutrition Foundation (CDHNF) a new resource for young adults with Inflammatory Bowel Disease (IBD) who are preparing for college, vocational training, entrance into the workforce or living independently.

Kids Health
www.kidshealth.org
Kids Health offers information about health, behavior, and development from before birth through the teen years, including links to information about: General Health; Emotions & Behavior; Growth & Development; Nutrition & Fitness; Recipes; Medical Problems; Q&A; Positive Parenting; First Aid & Safety; Doctors & Hospitals; Medications.

Government Related Sites:

Centers for Disease Control and Prevention
www.cdc.gov
"CDC is the nation's premiere health promotion, prevention, and preparedness agency and a global leader in public health." Find online information about diseases and conditions, healthy living, injury violence and safety and emergency preparedness.

National Institutes of Health
www.nih.gov
The National Institutes of Health (NIH) is the primary Federal agency for conducting and supporting medical research. By searching through the NIH website, you can find links to disease information and on-going nation wide research.

GLOSSARY

MEDICAL TERMS & HOSPITAL ABBREVIATIONS

Abscess	A pocket or collection of pus.
Albumin	A protein that is measured in blood tests. The level is a good indicator of overall nutrition.
5-aminosalicylic acid (5-ASA)	The active component of mesalamine.
Anemia	Lower than normal amounts of hemoglobin in the red cells of the blood.
Ankylosing Spondylitis	A form of spinal arthritis that strikes some people with IBD, and which sometimes causes fusion of the joints of the spine.
Arthralgia	Pains in the joints, frequently experienced by persons with IBD.
Arthritis	Inflammation of a joint, accompanied by pain, swelling, heat, or redness.
Aseptic Necrosis	A complication of the prolonged use of high-dose steroids, in which one or both of the hip joints may suddenly undergo massive deterioration.
Autoimmunity	An inflammatory reaction to one's own tissues.
Barium Enema	An x-ray examination of the colon and rectum after liquid barium has been infused through the rectum.
BE	See barium enema.
BID	Twice a day (Latin: bis in die).
Biopsy	A small piece of tissue taken from the body for examination under the microscope.
BP	Blood pressure.
C&S	Culture and sensitivity (test for bacteria in blood and urine samples).
CAT Scan	See CT scan
CBC	Complete blood count. A type of blood test.
CD	An abbreviation for Crohn's disease.
Clinical	Involving the direct observation and treatment of patients.
Colectomy	Removal of part or all of the colon.

Colon	The large intestine.
Colonoscopy	A test in which a flexible, lighted tube is inserted through the rectum to examine the colon.
Colostomy	A surgically created opening of the colon to the abdominal wall, allowing the diversion of fecal waste.
Comprehensive Metabolic Panel (CMP)	A lab test which allows for the measurement of 12 blood chemistries from a single blood sample.
CT Scan	Abbreviation for Computed Tomography Scan. A specialized type of x-ray study.
CXR	An abbreviation for chest x-ray.
Discharge Summary	A summary dictated by your physician during or after the hospital stay, including any tests or operations performed, laboratory data, your condition on discharge, and plans for follow-up care.
Distal	Closer to the anus; downstream.
Distension	An uncomfortable swelling in the abdomen, often caused by excessive amounts of gas and fluids in the intestine.
Dx	An abbreviation for diagnosis.
Dysplasia	Alterations in cells that may predict the development of cancer.
E. nodosum	See Erythema nodosum
ECG (EKG)	Electrocardiogram.
Edema	Accumulation of excessive amounts of fluid in the tissues, resulting in swelling.
Elemental Diet	A specially prepared liquid meal that is hypoallergenic.
Electrolytes	Acids, bases, and salts essential for maintaining life.
Endoscopy	The examination of the inside of a hollow organ, such as the bowel, using special lighted tubes.
Erythema Nodosum	Red swellings occasionally seen on the lower legs during flareups of Crohn's disease and ulcerative colitis.
ESR	Erythrocyte sedimentation rate. A type of blood test.
Exacerbation	An aggravation of symptoms or an increase in disease activity; a relapse.
Excision	Surgical removal.
Febrile	Running a fever.

Fissure	A crack in the skin; usually near the area of the anus in Crohn's disease.
Fistula	An abnormal connection between two locations in the body, such as loops of intestine, or between the intestine and another structure, such as the bladder,vagina, or skin.
Folic Acid	One of the vitamins responsible for the maintenance of red blood cells.
Fulminant	Disease that develops with extreme rapidity.
Gastroenterologist	A physician specially trained in the diagnosis and treatment of patients with gastrointestinal disease.
GI	Abbreviation for gastrointestinal.
Granuloma	Microscopic collections of cells characteristic of Crohn's disease.
Gut	General word for intestine or bowel.
H&H	Abbreviation for hemoglobin & hematocrit.
H&P	Abbreviation for history and physical examination.
HCT	Abbreviation for hematocrit.
Hematocrit	A measure of the number of red blood cells. Low levels are seen with anemia.
Hemoglobin	The molecule in red blood cells that carries oxygen. Low levels of hemoglobin result in anemia.
Hemorrhage	Abnormally heavy bleeding.
Hemorrhoids	Painful, dilated veins of the lower rectum and anus, sometimes seen as a complication in persons with IBD.
Hgb	Abbreviation for hemoglobin.
History and physical examination	Contains your complete medical history as told to the admitting resident, as well as results of physical examinations.
HPI	History of present illness.
Hyperalimentation	A means of supplying patients with additional nutritional support by vein so that their nutritional requirements are met. Also known as total parenteral nutrition (TPN).
IBD	Abbreviation for inflammatory bowel disease.
IBS	Abbreviation for irritable bowel syndrome.
Idiopathic	Of unknown cause.

Ileoanal Anastomosis	A newer operation for ulcerative colitis (also known as the pull-through) in which an internal pouch is created after colectomy Because the rectal tube is retained, the patient continues to evacuate through the anus.
Ileostomy	A surgically created opening of the abdominal wall to the ileum, allowing the diversion of fecal waste.
Ileum	The lower third of the small intestine, adjoining the colon.
Ileus	Temporary paralysis of the bowel, often resulting from sugery, abdominal infection, or electrolyte imbalance.
IM	Intramuscular.
Immunology	Study of the body's immune response to disease.
Immunomodulators	Drugs that suppress or amplify the body's immune response.
Incontinence	In IBD, the inability to retain feces, usually because of rectal inflammation.
Inflammatory	A collective term for Crohn's disease and ulcerative colitis.
Intractable	Unrelieved by medical treatment.
Irritable Bowel Syndrome	Altered motility of the small and large intestine, causing diarrhea and abdominal discomfort. Sometimes mistakenly called "spastic colitis," this condition does not cause inflammation of the colon and has no relationship to IBD.
IV	Abbreviation for intravenous, meaning into a vein.
Lactase Deficiency/ Lactose Intolerance	A condition caused by a decrease or absence of the enzyme lactase, which aids in the digestion of milk sugar (lactose).
Lactose Breath Test	A test involving the drinking of a liquid rich in milk sugar. Breath samples are then taken over a period of time to determine whether there is a deficiency in lactase.
Leukocytosis	An increased number of white blood cells in circulation; an indicator of infection.
Mesalamine	The generic name for 5-ASA, a relatively nontoxic and well-tolerated drug used to treat inflamed intestine.
Motility	Movement of the muscles that propel food through the intestinal tract.
MRE	MR enterography – an MRI of the intestines
Mucus	A clear or whitish substance produced by the intestine, which may be found in the stool.
Nasogastric Tube (NG Tube)	A thin, flexible tube passed through the nose or the mouth. Used to remove liquids and air that collect in the stomach when the bowel is obstructed or after intestinal surgery, or to deliver nutrients into the stomach.
NPO	Nothing by mouth (Latin: nihil per os).

Obstruction	A blockage of the small or large intestine that prevents the normal passage of intestinal contents.
Occult Blood	Nonvisible blood in the stool, often an indication of disease activity. Simple lab tests can determine the presence of occult blood.
Operative Report	A complete record of any operation dictated by the surgeon after surgery.
Ostomy	The surgical creation of an artifical excretory opening, such as a colostomy.
Pathogen	A bacterium or virus capable of causing disease.
Pathogenesis	The origin and development of disease.
Pathology Report	Results of examination of any tissues removed from your body at operation or biopsy.
Perforation	Formation of a hole in the bowel wall, allowing intestinal contents to enter the abdominal cavity.
Perianal	The area around the anal opening; This area may become inflamed and irritated in persons with IBD.
Peristalsis	Normal rhythmic movements of the stomach and intestine.
Peristomal	The area immediately surrounding the stoma.
Peritonitis	Inflammation of the peritoneum (the membrane enclosing the abdominal organs), usually resulting from an intestinal perforation.
PO	By mouth (Latin: per os).
Proctectomy	Removal of the rectum.
Proctitis	Inflammation of the rectum.
Proctocolectomy	Removal of the entire colon and rectum.
Progress Notes	A daily record of your progress, test results, etc., by the professionals who care for you.
Prolapse	The falling or protrusion of an organ, such as the rectum or stoma.
PRN	As needed (Latin: pro re nata).
Proximal	Closer to the mouth; upstream.
Pyoderma Gangrenosum	A type of sore that sometimes occurs on the extremities of persons with ulcerative colitis or Crohn's disease.
Q4H	Every four hours.

QD	Every day.
QID	Four times per day.
QOD	Every other day.
RBC	Abbreviation for red blood cell.
Regional Enteritis	Another name for Crohn's disease affecting the small intestine.
Remission	A lessening of symptoms and a return to good health.
Resection	Surgical removal of a diseased portion of intestine.
Reservoir	A surgically created pouch, made from the distal ileum, which collects waste.
RX	Medications.
S	Without (Latin: sans).
SBFT	Abbreviation for small bowel follow-through. Used when describing an upper GI study in which barium is followed all the way through the entire small intestine.
SED Rate	See ESR
Short Bowel Syndrome	A condition in which so much diseased bowel has been surgically removed that the remaining intestine can no longer absorb sufficient nutrients.
Sigmoidoscopy	A test in which a lighted tube is passed through the rectum into the sigmoid colon.
Stat	Immediately.
Small Bowel	Small intestine.
Sphincter	A ring of muscle tissue keeping certain sections of the digestive tract (e.g., the anus) closed.
Stenosis	A narrowing of an area (e.g., a segment of intestine).
Stoma	A surgically created opening of the bowel onto the skin, the result of ostomy surgery.
Stricture	A narrowed area of intestine caused by active inflammation or scar tissue.
Strictureplasty	A surgical procedure that widens narrowed areas of intestine (strictures).
Subtotal Colectomy	Removal of part or most of the colon, leaving a part (usually the rectum) intact.
Sutures	Materials used in surgery to rejoin cut tissues and close wounds.
Tenesmus	A persistent urge to empty the bowel, usually caused by inflammation of the rectum.

TID	Three times a day.
TPR	Temperature, pulse, and respiration.
Total Parenteral Nutrition (TPN)	The intravenous infusion of all nutrients through a catheter placed in a large vein near the collarbone. Also known as hyperalimentation.
Toxic Megacolon	Acute dilation of the colon in ulcerative colitis (or occasionally in Crohn's disease), which may lead to perforation.
TX	Abbreviation for treatment.
Upper G.I. Series (UGI)	An x-ray exam of the esophagus, stomach, and duodenum performed in the fasting patients after the ingestion of liquid barium. The duration of the exam can be prolonged to allow for visualization of the entire small intestine, including the terminal ileum. The x-ray is then known as an upper G.I. series with small-bowel follow-through.
US or U/S	Ultrasound.
WBC	White blood cell.
WNL	Within normal limits.
X-ray Reports	Results of diagnostic x-rays.

History Overview

Date of diagnosis: ____________
Physician who made diagnosis: Dr._________________ Hospital ________________________

Procedures Performed: *Procedures that should be listed here include colonoscopies, upper endoscopies, x-rays, and surgeries.*

- *Insert copies of the reports from these procedures in the Procedure Records Section*

Procedure	**Date Performed**	**Location**	**Reason for Procedure & Results of Procedure**

Hospitalizations

- *Insert copies of your discharge letters in the Correspondence & Appointment Records Section*

Date Admitted	Date Discharged	Location	Reason For Admission	Discharge Instructions

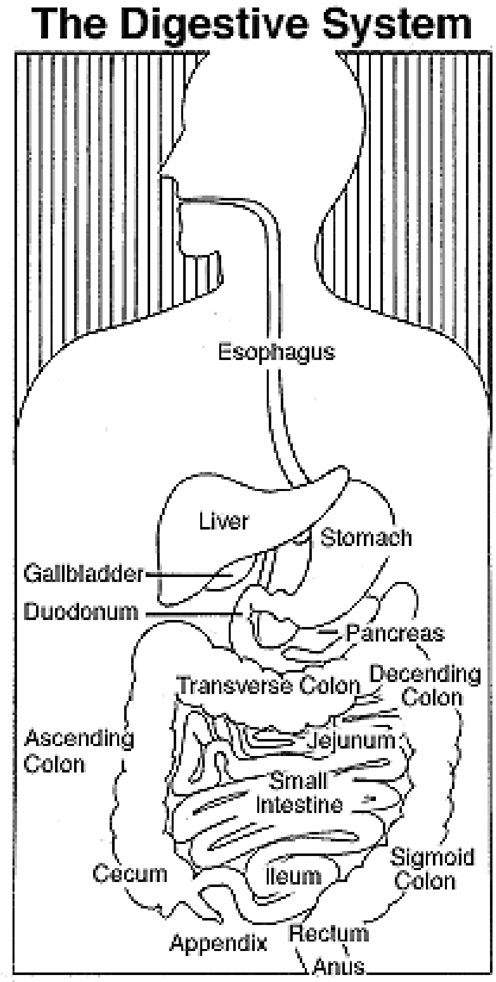
Medical and Environmental Allergies: ***Please include any reactions you have had to medications, foods, or environment.***

Allergy To	Date Identified	Reaction and Treatment

Additional Medical Conditions

Condition	Date Diagnosed	Who Manages This Condition	Treatment for Condition
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	
		Dr ___________________ Hospital ______________	

Disease Location



Doctor's use colonoscopies, x rays, and other procedures to identify where in your digestive system your disease is located. Record on the chart below where, how, and when the location of your disease was identified

Location	How, When Identified
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________
	Date______________________ Procedure__________________

<u>Extra-intestinal Problems:</u> *Problems with IBD often occur outside of the digestive system (extra-intestinal). The most common problems are listed below. If you have had any of these problems, please indicate when and/or where these problems occur.*

Problem	When or Where Does the Problem Occur
High Fevers	
Mouth Sores	
Joint Pain	
Skin Rashes	
E Nodosum (red, painful lumps)	
P Gangrenosum (skin ulcers)	
Eye Problems (uveitis)	
Perianal Disease	

Medical Therapy Records

When you start a new dose of a drug you are currently on, please record the stop date and then on a separate line the start date of the new dose.

5-ASA Therapy

- *These include: Asacol, Pentasa, Azulfidine, Colazal, Rowasa, Canasa, and Dipentum*

Medication	**Date** Started	Date ***Stopped***	**Dose**	**Precautions** ***Side Effects*** ***Allergic Reactions***

Antibiotic Therapy

- *These include: Flagyl, Cipro, or other antibiotics used to treat your IBD.*

Medication	**Date** Started	Date ***Stopped***	**Dose**	**Precautions** ***Side Effects*** ***Allergic Reactions***

Steroid Therapy

- *These include: Prednisone, Budesonide, Medrol, or Methylprednisone*

Steroid	Dose	Date Started	Date Stopped	*Problems* Side Effects Allergic Reactions

Immunomodulator Therapy

- *These include: 6-MP, Azathioprine, or Methotrexate*

Medication	**Date** Started	Date ***Stopped***	**Dose**	**Precautions** ***Side Effects*** ***Allergic Reactions***

Biologic Therapy

- *These include: Infliximab (Remicade), CDP-571, Natalizumab (Antigren), D2E7 (Humira)*

Infusion Date	Dose	Weight	Pre-Medication (Tylenol, benedryl, medrol etc)	Problems During Infusion

Other Prescription Medical Therapies

- *These include: Other therapies such as Cyclosporine, Thalidomide, Entanercept, Mycophenolate Mofetil, Tacrolimus or medications you may have received as part of a clinical trial.*

Medication	**Date** Started	Date ***Stopped***	**Dose**	**Precautions** ***Side Effects*** ***Allergic Reactions***

Nutritional Therapies: *Please record in this table any use of nutritional therapies such as NG Tube Feeds. Record how it is delivered (tube feeding, can) and any notes about the therapy (problems, suggestions, etc)*

Type	**Date** Started	Date ***Stopped***	**Amount**	***How is it Delivered and Notes About Therapy***

Non Prescription Therapies: *Please record in this table any use of other treatments (fish oil, probiotics, prebiotics etc), over the counter medications (vitamins, Imodium etc), or use of specialists (acupuncture, yoga, massage etc)*

Therapy	Dose	Date Started	Date Stopped	Notes Regarding Therapy

Additional Information: *Use this space to record any additional info regarding your medical therapy.*

Procedure Records

Following this page

- ***Please place copies of reports from Colonoscopies, Upper Endoscopies, X-Rays, and Surgeries***
- Please place these records in order beginning with your most recent procedure.

Lab Test Records

Following this page

- Please insert copies of the results from your blood tests, stool cultures, and any other lab work.
- Please place these records in order starting with your most recent laboratory test.

PLAN FOR MEDICAL EMERGENCY

Before traveling discuss with your doctor how best to handle a medical emergency in the area to which you are traveling. Please record below your doctor's suggestions, as well as important numbers in the area to which you are traveling (doctors, hospitals etc)

PLAN

____

____

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NUMBERS

International Association for Medical Assistance (716) 754-4883

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Nutrition

How is Crohn's disease and ulcerative colitis related to nutrition?

The GI tract, especially the small intestine, is where food is broken down so the body can use it. When the intestine is inflamed it is not able to break down food as well. Then the body is not able to get the nutrition it needs to stay healthy or grow. There is often pain or diarrhea when this happens. When the intestine is very inflamed the diarrhea can become very severe and sometimes have blood in it.

Was it something I ate?

No. There is no food (or drink) that causes IBD. For some people certain foods will bother them but each person is different and not everyone will be affected.

Do I need to follow a special diet now?

No, not really. It is important that you eat a healthy, well balanced diet so you can be healthy and grow normally. You can pretty much go on eating the same way you did before you became sick, but if there are any foods that bother you, you should stay away from them.
One of our dietitians can meet with you to review your diet to make sure it is good for you.

Should I take a vitamin?

That depends. If you are able to eat a healthy diet you probably don't need a vitamin. BUT if you think you are having trouble eating healthy then you may want to take a multivitamin.
Sometimes your doctor will prescribe an iron supplement if you have had blood in your stools. We also want to make sure that you are getting enough calcium to keep your bones strong.
The dietitian will tell you if you how to get iron and calcium from your diet and whether you need a multivitamin or calcium supplement.

What happens if I can't eat enough to gain weight or grow?

The childhood and teenage years are when you grow the most. If it is too hard for you to eat enough to gain weight or grow it is important to let us know. We can work with you to make sure that your IBD is in remission and to choose the right foods. Sometimes it is just to hard to eat enough and we will talk about other ways to help you get nutrition.

HOSPITALIZATION

During the course of your care you might have to spend time overnight at the hospital for tests, for special treatment of your disease, or for surgery. The hospital may seem like a strange and unfamiliar place, but if you know what to expect, your stay can be a lot more pleasant for everybody. We have included some tips that patients have given us that made their stay in the hospital more comfortable, and we have left space for your to write your own tips.

Our Tips

- Leave all valuables at home as they may be lost in the shuffle, but do bring some cash ($30) to pay for minor expenses you may have while hospitalized.
- Bring comfortable clothes, and make sure to bring clothes for any type of temperature as it can go from hot to cold depending on where you are. Slippers are also great to help you feel at home.
- Lifesaver candies are great to have especially when you are not allowed to eat solid food.
- Bring your own bathroom accessories unless you do not mind using the ones that the hospital provides.
- Bring telephone numbers and addresses of people you might want to contact, as well as writing materials to make notes about questions you have for doctors and to record information.
- Bring your medications with you. If the hospital does not have your medication they will dispense yours until they do.
- Bring some reading/entertainment materials like magazines or a walkman. Patients can often bring their video games to hook up to hospital televisions, as well as videotapes to watch on hospital VCRs.
- Read the pages about “Your GI Team”. You should also familiarize yourself with the schedule that you will have in the hospital. Sleeping can be difficult so know when you can, and when you might be woken up.
- Some hospitals have a library of information for patients and their families including Internet access, journals, and videotapes. Ask your nurse about these resources.

Your Tips

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IBD & School

Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act ("ADA"), and the Individuals with Disabilities Education Act ("IDEA") are all parts of the Federal Law created to protect individual rights within the public domain. These laws provide guidelines to help identify the health care-related needs of students with disabilities, as well as services and accommodations that should be provided to those students.

Given a diagnosis of Crohn's or Ulcerative Colitis, a patient is considered a person with a disability under Section 504 and the ADA because the illness can significantly impair in performance of the major life activity of caring for one's self (i.e. the act of disposing of bodily waste has been impacted). The Americans with Disability Act requires that students with disabilities be given accommodations to allow them to participate in a classroom in the "least restrictive learning environment."

Patients diagnosed with IBD who are already involved in the special education system due to other educational needs, may only need to amend their current IEPs in order to allow for medical accommodations related to their IBD needs in the classroom.

Given that many patients diagnosed with IBD function quite well the classroom, these patients may not already be receiving special education services. Therefore, it is your right as a parent to ask that a 504 Plan be written and implemented to allow for medical accommodations in the classroom related to your child's IBD. The school will most likely require documentation from your child's medical team to confirm the diagnosis and discuss recommendations for accommodations in the classroom. Here are some examples of IBD accommodations:

1) Keeping a water bottle at desk his/her desk to stay hydrated
2) Free access to restroom without explanation
3) A modified Gym class
4) Access to an area to rest
5) Extra time for assignments when needed due to hospitalization
6) Makeup quizzes without penalty due to absence
7) Extra time on timed-tests to account for bathroom use
8) An option for extra one-on-one assistance to keep pace with peers if hospitalized

If you are interested in learning more about 504 Plans and/or need documentation for your child's school, please contact **Stephanie Atlas, LICSW at 401-444-3247**, or ask the GI clinic to page Stephanie at your next appointment.

IBD & Going to College

*Just as a 504 plan can be helpful during elementary, middle and high school, having such a plan in place can be extremely useful in transition to college.

*Before you even go to college, your 504 Plan may allow you to have extended time on your SATs and other time limited entrance exams. Speak with the SAT board, or whoever is running the test to determine what paperwork may be necessary

*It is important to remember that it is your decision about who you share your diagnosis with. However, working with school administration, especially when heading to college can be incredible important in the long run.

*By preparing ahead of time, if you should have a flare while at school, you'll know the correct people to talk to, how to communicate with your teachers and how to get the help you need.

*Once you have determined which college you are going to attend, it will be important to contact your school to learn their policies about special circumstances, their health care services, and what resources might be available to you.

*Typically, the Student Services office will be able to point you in the right direction. On many college campuses, 504 Plans and medical accommodations coordinated by the Office for Students with Disabilities

*Just as you had accommodations during high school, there are things that might be helpful in considering college life (here are some helpful hints from out friends at NASPGHAN):

> *Special bathroom passes can usually be secured for students with IBD, and special accommodations can sometimes be arranged (such as a private bathroom in your college dorm room). At the very least, plan ahead for bathroom trips.
>
> *Many schools will provide note takers for students who have trouble getting to class; check with your school for what services it offers students with special circumstances.
>
> *Don't sacrifice meals at the expense of school, keep handy some calorie supplements that can be "meals in a can" in case you find yourself rushed or at the library late.
>
> *Always keep extra medication on you at all times.
>
> *Make your teachers aware of your circumstances before the semester starts, so hopefully they will understand if you are absent or late."

IBD & Traveling

Thanks to our friends at NASPGHAN, here are some helpful hints when traveling!

- **Never put your medication or important information in luggage that leaves your possession. When traveling by plane, bring your meds and your notebook with you in your carry-on luggage.**
- Be careful of the water! Always drink bottled water wherever you go. Every country has different bacteria that their native digestive tracts are used to, while yours may not be.
- Beware of exotic foods. Your digestive system may not easily handle such changes in diet, so check with your doctor before you leave if you want to sample the local cuisine.
- Make sure you have appropriate accommodations, such as bathrooms for long trips.
- Bring toilet paper or wipes with you, don't get stranded empty handed (companies make handy travel packs of 10 wipes that can fit into a pocket).
- Be knowledgeable of some basic language in the country you are visiting: especially phrases like "where's the bathroom" or words like "hospital, pharmacy, and doctor". Consider keeping a cheat sheet in your wallet.
- Keep a few handy nutritional supplements around in case you find yourself in need of a meal while in transit. This is probably not the best time to be skipping a meal.
- Bring a summary of your medical history – it could come in very handy if you are not feeling well and need to visit a local, unfamiliar, hospital.

Psychosocial Issues in Children and Adolescents with IBD

"Having an illness does not require that a child stop doing the things they enjoy. What having an illness requires is that the child must start planning ahead about things in their daily life, such as travel or school. At first this planning might be difficult, however, with time it will become much easier and will help to give you a more normal and safe life."
~NASPGHAN IBD Notebook

A New Diagnosis

How will a new diagnosis of IBD affect my child psychologically?

Children and adolescents have a variety of emotional reactions to a new diagnosis of IBD. They may feel anxious, sad, or angry. They may also feel optimistic and confident about handling the disease and not experience any strong negative reactions to the news. Some kids temporarily act younger than their ages or seem more dependent on their parents for reassurance and help with taking care of themselves. These are all normal reactions. It can be helpful to remember that children and teens will not always feel the way they do when they're first diagnosed. Kids and their families adjust to the new information and having physical symptoms under control, once the medical treatment has begun, goes a long way in improving how kids feel emotionally.

Can my child live a normal life in spite of having IBD?

The answer is "yes!" There will be ups and downs in your child's physical and mental health. When your child is in the middle of a flare-up and their symptoms are bothering them, IBD may seem inconvenient and distressing for your child and for your family. However, periods like these don't last forever, and in between those times, your child will likely want to get back to a normal routine and focus on just being a kid. Any chronic illness, including IBD, creates challenges for children, teens, and families. However, with medical treatment, family support, and the assistance of their GI team, kids with Crohn's and Colitis can excel in school; enjoy family life, sports, and hobbies; have great friends; and live pretty normal lives.

Did stress and anxiety cause IBD in my child/adolescent?

No. Crohn's and Colitis are biological disorders and are not caused by stress, anxiety, or depression. However, the symptoms of many diseases can get worse in stressful situations, even though the stress did not initially cause the disease. Stress and negative emotions may affect symptoms once a child/teen has IBD. At times of physical or emotional stress, some children/adolescents have flare-ups of their symptoms, experiencing more abdominal pain or diarrhea.

I feel guilty, angry, and sad that I somehow brought on IBD in my child. Is this justified?

While we know that Crohn's disease and ulcerative colitis tend to run in families, only 5-7% of kids develop Crohn's if one parent has Crohn's. Even fewer than 5% develop ulcerative colitis, if one parent has it. At this time, there does not seem to be any clear-cut pattern to family inheritance. If you do have a family history of IBD, this is not something you can change. Clearly, you did not wish for your child to develop IBD. However, looking forward, there are many things that you can do, as a parent, to help your child or teen manage their disease and lead a healthy, happy life.

Social

My child/adolescent used to be very social. After getting sick and diagnosed with IBD, he/she is less interested in being with friends. Why? What can I do to help?

The symptoms of IBD sometimes get in the way of children's social lives. Sometimes children and adolescents with IBD are reluctant to go to events that center around food because of changes in appetite or restrictions in their diets. In addition, cortisone-type drugs, such as prednisone, may cause weight gain and changes in appearance (e.g., puffy face, acne). Other kids become moody and restless. These changes in appearance, mood, and behavior may cause children and teenagers to feel uncomfortable with peers. It is important to help kids with IBD to stay active with their friends in and out of school and to encourage them to stay involved with their hobbies and extracurricular activities. Your child should be encouraged, if comfortable, to tell close friends about their illness. This can help them receive support from their friends and avoid a sense of secrecy and shame. Some children and teens have even benefited from making presentations to their class about IBD or having their parents, the teacher, or a school nurse do so. This helps classmates understand what they've been going through and can help friends to be supportive. Every child/adolescent will make their own decisions about who they feel comfortable sharing their diagnosis with and the pace at which they're comfortable getting back into their social scene.

School

My child is missing so much school. Is this common in children with IBD?

Missing school is a common problem for children with any chronic illness. There are many different reasons why kids with IBD may miss school. Hospitalizations, doctor's appointments, tests, frequent pain and fatigue may affect your child's ability to get up, go to school, and concentrate. Some children with IBD avoid school out of fear of negative reactions to their appearance, having to explain why they've been absent, not being able to participate in sports or activities, being too far behind with schoolwork, or lack of understanding from teachers. In addition, they may worry about needing to leave the classroom quickly to use the bathroom. If you find this happening, it may be helpful to speak with your GI doctor for a referral to the GI social worker or pediatric psychologists. Your team has lots of experience with helping kids with IBD and their school to make arrangements that lead to more comfort and success as school.

What can I do if my child/adolescent is falling behind in school?

If your child's school performance is slipping, a catch-up plan should be developed together with your child's school system and teacher. This should include supplementary tutoring, some individualized instruction, or a "504-plan" (specifically tailored to help students with special needs/medical accommodations feel comfortable within the regular learning environment)*. Such proactive efforts can help children/adolescents with IBD develop a sense of accomplishment. They can also decrease the risk of negative attitudes toward school if the child/adolescent feels ashamed or overwhelmed by poor academic performance. If you need more assistance working with your child's school, we can help.

*PLEASE SEE THE FOLLOWING PAGES FOR MORE INFORMATION ON HOW TO OBTAIN A 504 PLAN FOR YOUR CHILD.

Adolescence

It seems like as my child has become older and has become a teenager he/she has stopped caring for their IBD (i.e., taking medication as scheduled, avoiding troublesome foods, etc.). Is this common?

Difficulty following medical recommendations (nonadherence) is a common problem among adolescents with chronic illness. Adolescence is a time when we seek to become more independent and more self-sufficient as a part of growing up. Chronic illness may push teenagers to become more dependent on their families or healthcare providers. This can be a particularly difficult adjustment for adolescents, when kids focus a lot on how they look and fit in with peers. It can be a challenge for teens to take meds that may cause changes in physical appearance or to manage their IBD in a way that makes them feel different from their peers. Therefore, it is not surprising that emotional difficulties, often denial of illness and feeling "burnt out" from IBD, may be somewhat greater among teenagers. Teen have lives that are busier with schoolwork, sports, jobs, friends, and dating relationships. They also spend less time with parent. All of these things can make routines, including taking medication, harder to manage. It's no wonder that many teenagers have difficulty taking care of their disease exactly as prescribed! However, many teens do very well with taking care of their IBD, and lapses in care should never be ignored.

How can I help my adolescent with IBD lead a healthy life?

Even though there are reasons why taking care of IBD may be more challenging for teens than kids at other ages, it should still be addressed. The GI team can help teens and parents to figure out ways to get back on track with IBD care. Adolescents should gradually be encouraged to participate in their own care, including keeping track of medications and diet, making phone calls to physicians and nurses, participating in physical examinations alone, participating in making treatment choices as much as is possible, etc. As a parent, it is important to be aware of your adolescent's need for independence and allow this as much as is appropriate and possible. However, teens still need their parents to supervise their overall care and help them when they hit snags along the way. As adolescents demonstrate their ability to take responsibility for their own health, parents can hand over the reins step by step. In addition, adolescents should be encouraged and supported in engaging in normal activities, since being successful at school and having a healthy social life are important for overall quality of life.

Coping

Are resources available for helping our family adjust to this diagnosis?

Your GI team includes several professionals who have specialized training in helping children and adolescents adjust to IBD. This GI psychosocial team includes child life specialists, social workers, and pediatric psychologists. The GI psychosocial team works with children and adolescents individually, with their families, and within the IBD support group. They attempt to meet every family to introduce the psychosocial services available, but if you haven't met them, ask your GI physician who will arrange to have you meet a member of the psychosocial team.

Some children and adolescents meet with the social worker or psychologist once or twice for a "check-up" to see how things are going with their adjustment to IBD and to learn about red flags for figuring out when they might need to work with a psychologist in the future. Some kids meet the pediatric psychologist regularly for a short period of time to work on something specific, like taking medications more regularly or dealing with stress or anxiety. Other children and adolescents meet with the psychologist at regular intervals, such as once or twice a year, to check in on how they're doing living their lives with IBD.

What red flags would suggest that my child needs psychological support for coping with IBD?

- Poor understanding of IBD
- Difficulty with blood draws or other medical procedures
- Depressed mood
- Anxiety
- Excessive anger
- Conflict with parents
- Sleeping too little or too much
- Avoiding school
- Avoiding social activities
- Difficulty taking medications

Pediatric Psychologists

In its treatment of chronic illness, the pediatric gastroenterology, nutrition and liver diseases department recognizes that physical health, mental well-being and behavior cannot be separated. Therefore, pediatric psychologists are an important part of the multidisciplinary team that serves our children and families.

Who are pediatric psychologists and what do we do?
Pediatric psychologists are specially trained to provide behavioral and mental health interventions to children and adolescents in medical settings. They are available to educate families about the psychological, emotional and social effects of physical symptoms and illnesses on children and to assess their emotional and behavioral functioning. They also provide treatment services with the goals of enhancing kids' and families' adjustment to a medical diagnosis; helping kids and families follow their treatment regimen, whether it involves taking medication or making changes in their routines; and teaching children skills for managing pain and coping with stress.

Pediatric psychologists work closely with the GI physicians, nurses, social workers, dietitians, and child life specialists to ensure that children's emotional, behavioral, and social functioning is addressed alongside their medical needs. Families can access psychological services by talking to their GI physician, or the GI social worker, who will help arrange a consultation.

Pediatric GI Nurses

Adjusting to a new illness and learning to navigate the healthcare system are difficult tasks. The pediatric GI nurses will be available to provide support, education and resources to you and your family during the difficult times.

Who are the pediatric GI nurses and what do we do?

- The pediatric GI nurses are licensed professional nurses.
- We are available to provide IBD education and to help you locate educational resources.
- We will assist you to communicate your need to members of the GI Team, other healthcare providers while in the hospital or outpatient setting and act as an advocate for you and your child.
- A telephone consultation with the GI nurses is available by calling the Nurse Line 401-444-5805 Monday through Fridays (closed on holidays and weekends) 8:30 am until 4pm.*

We can assist you with:

- Questions about your child's illness or when he/she has a "flare".
- Medication concerns and issues
- Education
- Coordination of care
- General medical information
- Guidance to assist you with "Pre-Authorization issues".

- The pediatric GI Nurses are members of the IBD Support Group and will be there to answer questions and provide education.

*A nurse can usually be reached by pager after hours 401-350-4237. If you call is not returned with in fifteen minutes and your need is urgent please page the GI Fellow on call by contacting the page operator 444-5611 and press "0".

Pedi GI Clinical Social Work

Hospitalization and illness can be a stressful experience. Everyday problems become more difficult to manage. The Pedi GI Service offers clinical social work services to help your family during this difficult time.

Who are clinical social workers and what do we do?
Clinical social workers are licensed professionals trained to help you and your family manage the emotional and social problems related to illness and hospitalization. Social workers can help your family manage problems that arise because of an illness, such as adjusting to the diagnosis, dealing with relationships, and returning to work or school. We are available to discuss these issues and provide counseling services when needed. We are also informed about community services and can refer you to helpful agencies and other resources when appropriate.

By law, your communication with your social worker is protected and cannot be released without your consent. However, some information may be shared with your healthcare team in order to ensure all of your questions are answered.

Our social workers are available to you and your family to provide support and access to resources both in the hospital and in the clinic. They are available to assist you in communicating your child's needs and your concerns to the medical team, as well as communicating with your child's school to ensure he or she gets all of the educational services he or she is entitled to receive.

In addition to individual support services, social workers and child life specialists co-lead the Inflammatory Bowel Disease (IBD) Patient Support Group. This group is available to all pediatric GI patients diagnosed with any form of IBD. The group provides a safe and supportive environment for IBD patients to connect with peers with similar conditions.

If you are interested in pediatric GI social work services or have questions regarding adjustment to illness and/or access to resources, including insurance issues, please contact the social work department at **401-444-5711.**

If you are hospitalized or in the clinic and would like to speak to a social worker, please have a nurse page a pediatric GI social worker.

Child Life Services in the Pediatric GI Clinic

Coming to the hospital can be a scary experience. Strange places, new faces can be confusing and upsetting for patients and families. Child Life Services in the Pediatric GI Clinic can help a child and family become familiar with this new environment and address any fears that may arise.

Who are Child Life Specialists and what do we do?

Certified Child Life Specialists are professionals who are trained in the areas of Child Life Development, Play and Psychology. They have been specially trained to work with children who are dealing with their concerns and reactions to both hospitalization and illness. They help to promote optimum development in children by reducing stress through preparation and education. Child Life Specialists offer choices in order to better help patients to feel independent, build their self-esteem, and feel in control. The Child Life Specialist also works to assist families in maintaining normalcy and enhancing coping abilities. As a member of the medical team, Child Life works to create an atmosphere that is Family Centered and therapeutic. The Child Life Specialist is an advocate; competent and available to help patients and families through their medical experiences and visits to the GI clinic.

Services Child Life can provide during GI clinic visits include:

- Preparations for tests, procedures, and/or surgery through the use of developmentally appropriate medical play and of teaching materials.
- Support for a patients and/or families during a procedure by providing emotional support and/or distraction.
- Choices; which allow patients a chance to make decisions, practice present skills and master new ones.

In addition to individual support service, Child Life co-leads the IBD Patient Support Group with the Pediatric GI Social Worker. This is a group available to all Pedi GI patients diagnosed with any form, of IBD. The group provides a safe and supportive environment for IBD patients to connect with peers with similar diagnosis.

If you are interested in Child Life Services or have questions regarding The IBD Patient Support Group please contact the Child Life Specialist at 401.444.5613.

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My child is having difficulty with medical procedures. How can I help?

A new diagnosis of IBD involves many tests and procedures such as blood work, endoscopies, and colonscopies. This can create anxiety for both children and families for many reasons. Patients feel a loss of sense of control due to diagnosis and/or hospitalization. Children and families may have lots of questions regarding procedures, diagnosis, and the hospital and may already have concerns based on previous experiences. Most children and adolescents cope better with procedures and tests when prepared before the actual event. Understanding what will happen and how they can cope with procedures helps to return a sense of control to the patient and family. The GI psychosocial team can help you and your child be better prepared for tests and procedures through relaxation techniques, medical play and preparation tools, and support during actual procedures.