

# INFLAMMATORY BOWEL DISEASE TEACHING PACKET

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## Office Policy Concerning Phone Calls

**Main Phone Number: 708-684-5650** This is the number you need to call all the time, regardless of where you are seen. The phone line is open Monday through Friday from 9a to 4p. After 4p, that line will direct you on how to get in touch with the physician if there is a medical emergency. There are prompts for you to listen to. Option 1 is to make appointments. There are options to speak to the nurse and it is broken down into what office you are seen at. For lab results, questions and prescription problems, you need to press the prompt for the office you are seen at. If you have infusion issues and you receive your infusions at Edward, you need to press the option for the Naperville nurse line. The **BIG EXCEPTION** is when your child is having a **FLARE**. A flare is defined in this handout on the page, When You Need to Notify Us. During a flare, you **ALWAYS** need to press the nurse prompt for Evergreen Park. There is always the potential that you will require hospitalization during a flare, and that is why we ask you to notify the Evergreen Park nurse during a flare. We want you to get the care your child needs in a prompt time frame.

## Understanding Inflammatory Bowel Disease

Basic knowledge of inflammatory bowel disease will help you understand and recognize your symptoms. This will help with the management of your disease.

Inflammatory Bowel Disease (IBD) is a chronic inflammation of the intestines that is not due to infection. The immune system is overactive and leads to injury of your intestines. There are two main types of IBD: Crohn's disease and ulcerative colitis. Crohn's disease can affect any part of the gastrointestinal tract from the mouth to the anus. Ulcerative colitis usually involves only the large intestine, which is also called the colon.

Over 1 million Americans suffer from IBD and it occurs in both children and adults. IBD is thought to be caused by a combination of both genetic and environmental factors which lead to injury of the intestines. Research is constantly being done to better understand IBD. IBD is not to be confused with irritable bowel syndrome (IBS).

### Signs and Symptoms of IBD May Include:

- Abdominal Pain
- Diarrhea or bloody bowel movements
- Weight loss or poor growth
- Fatigue/Decreased energy level
- Unexplained fevers, joint pains or mouth sores
- Anemia (low red blood cell count)

## When You Need to Notify US

Regardless of what office you are seen in, when you have a flare, you need to call the nurse line for Evergreen Park during regular business hours. (Monday through Friday up until 4p). When a child has a flare, there is always the possibility of needing a hospital admission. Nurse Tricia will be able to address your concerns in a timely manner.

You should expect us to identify symptoms of a flare and respond to your concerns in a prompt timeframe. We are available to help answer your questions.

We expect you to be able to identify symptoms of a flare and call us at the earliest onset of symptoms. You should be able to identify what medications you are on and the correct dosage. We expect you to take your medications as prescribed.

A flare is an episode when IBD symptoms reappear. This can happen even if you are taking your medications as prescribed. It is important for you to notify us as soon as symptoms occur so we can provide you with the best treatment. This may prevent some of the complications associated with IBD.

### **Symptoms to be Concerned About:**

- Abdominal pain
- Blood in bowel movements
- Diarrhea/Increased bowel movements
- Nausea/Vomiting
- Fevers
- Joint pain
- Fatigue
- Change in Appetite

If you call us with urgent concerns, we will call you back within the day. For non-urgent matters, we will contact you within 1 to 2 days. If you need a refill on your prescriptions, please allow us 1-2 days for this to be completed. If you attempt a refill over the weekend, it will not be addressed until the next business day

**Please call Tricia, RN at 708-684-5687 on Monday – Friday from 9a to 4p. If you call after that time or on the weekend, you will not get a call back until the next business day.**

**When the office is closed, please call 708-684-5650 and ask for the doctor on call to be paged**

## Treatment of Your Disease

There are five goals in the treatment of IBD

1. **Induce remission:** This means to make you symptom free. You should not have pain , diarrhea or blood in yours stools. We will educate you about all the medications available to date. We will discuss the benefits and potential side effects of the medications prescribed and the toxicity, if appropriate.
2. **Maintain remission:** You may have read or your physician may have educated you about flares and remissions in IBD. Once we achieve a remission, we will keep you on medications that will prevent the recurrence of your symptoms. The goal is to keep you in remission.
3. **Nutrition and nutritional rehabilitation:** This is discussed under nutrition
4. **Prevention of complications:** This is maintained by regular follow up examinations. We want to see you every three to four months.
5. **Education:** It is a very important tool that we focus on. Depending on your age, it may be important to read about Inflammatory Bowel Disease and that understanding will help you now and in the future. Some of our patients are young and choose not to read about it. We respect that decision and encourage them to continue as they wish. We encourage parents to be well educated on IBD as well.

We expect you to take your medications exactly as prescribed. You need to make appointments with us every 3 to 4 months. You should call the office 2-3 weeks before your appointment to receive lab orders if they were not given to you during your last appointment. You need to let us know if you are having any problems taking your medications.

Medication prescribed for IBD needs to be taken as prescribed. If too much medication is taken, it can be harmful. If you do not take it as prescribed, it may not help you. Some medications have side effects that we need to monitor. That is the reason for appointments 3 to 4 times a year. We need to do a physical assessment and monitor your labs to prevent any dangerous side effects. Below is a list of some of the medications you may be prescribed to help manage your disease.

### **PREDNISONE**

Prednisone is a medicine known as a corticosteroid. It is similar to hormones made by the body and helps to reduce inflammation. Prednisone may slow down your body's natural production of these hormones. Therefore, it is important to follow the weaning directions as ordered. The body will slowly begin to make more of the natural hormones as the dosage is weaned.

Side effects of Prednisone can include weight gain, hunger, changes in mood and difficulty sleeping. These side effects improve as the dose is weaned. Other side effects can include bone weakening, an increased risk of infection, high blood pressure, elevated blood sugars and stomach irritation. It is important that you are up to date on your vaccines if you are taking Prednisone and undergo regular eye examines.

### **MESALAMINE**

Mesalamine is an aspirin-like medicine which helps control IBD. It can be taken orally, by a suppository or by an enema. Examples of mesalamine products include: Asacol, Asacol HD, Pentasa, Canasa, Lialda, Apriso and Rowasa. Rare side effects of these medications include allergic reactions, pancreatitis, and kidney injury. Make sure you wear sunscreen when outside to reduce the risk of skin rashes and sunburn.

## **MERCAPTOPURINE(6MP)/AZATHIOPRINE**

These medications are immunosuppressants and help reduce inflammation to the gastrointestinal tract. They do not work right away, so you may need to be on a combination of drugs at first until they take effect. Blood tests should be done every 3 to 4 months to check for possible side effects. We need to watch the white blood cell count closely as well as liver enzymes. When you are on these medications it is important to watch your sun exposure.

## **METHOTREXATE**

Methotrexate is another medication that suppresses the immune system. It can be given orally or by injection. This is another medication which requires frequent monitoring of labs. Pregnant women or women planning to become pregnant should not take this medication.

## **ANTI-TUMOR NECROSIS FACTOR MEDICATIONS**

Medications in this group include Remicade, Humira and Cimzia. They block the action of a protein in the body called TNF-alpha. A person with IBD may produce too much TNF-alpha which can cause inflammation. Remicade is given as an IV infusion and takes about 2 hours to infuse. The frequency of infusion varies depending on your symptoms. Humira is given by injection every 2 weeks and Cimzia is usually given by injection once a month. A TB skin test and chest xray should be done prior to starting these medications. Labs should be done every 3 to 4 months to check for possible side effects.

### **Important things to know about these medications:**

- If you have an HMO and you are on Remicade, you will need to bring a referral with you for the infusions. This is obtained by your primary MD.



- If your insurance requires prior authorization for Remicade, you need to keep track of the dates when authorization expires. Please do not wait to tell us a few days prior to expiration. We would appreciate knowing at least 2 weeks in advance, since this can be a time consuming process.

Please be aware that medications are always the first option of treatment for patients with IBD. However, some patients may develop complications that require surgery.

## Testing that May Be Ordered

### **Blood Work**

It is important to obtain blood work on a regular basis to monitor your disease and the effects of your medications. We like to get blood work every 3 to 4 months on our IBD patients. It is always best to obtain the lab work before your appointment with us. If you were not given a prescription for labs at your last appointment, please call our office 10 days before your appointment so that we can send the order to the appropriate lab. Below is a list of frequent blood tests:

- CBC – this checks for anemia and signs of infection. It also checks for potential side effects with certain medications
- Liver Enzymes – these can let us know of possible side effects of medications or complications of IBD
- ESR or CRP – these tests evaluate for inflammation
- Thiopurine Metabolites – this test measures the level of the medication in your system and helps us determine whether you are receiving the correct dosage.

### **Stool Studies**

If you are having symptoms of a flare, we may order stool studies to check for infection or inflammation

### **Radiology Studies**

A CT Scan, MRI or upper GI series may be needed if you are having complications. These tests help us look for signs of inflammation.

## Upper Endoscopy and Colonoscopy

### **Upper Endoscopy (EGD)**

An EGD test is done to examine the lining of the esophagus, stomach and duodenum. (The duodenum is the first part of the small intestine.) It is done with a flexible tube which has a light and camera on the end. The doctor looks for redness, swelling, bleeding, ulcers and infection. Biopsies, also known as small tissue samples, will be collected and looked at under a microscope by a pathologist.

### **Colonoscopy**

A colonoscopy is a test similar to an EGD except that it is done to examine the entire colon, also known as the large intestine. You will need to follow the directions for a "cleanout" in order for the test to be performed. This is a two day preparation which includes certain medications and a clear liquid diet the day before the procedure. It is very important to follow the cleanout as prescribed in order for the colonoscopy to be successful

### **Important Facts to Know with EGD and Colonoscopy**

- **Avoid red liquids the day before the procedure**
- **Do not take Aspirin or Ibuprofen**
- **Follow nothing by mouth orders as directed. Otherwise, the test may not be performed.**
- **These tests are usually done as an outpatient procedure. Plan on being in the hospital for 3 to 4 hours. You will be discharged from the hospital once you are awake and have had something to drink.**
- **You may experience some bloating, abdominal cramping, nausea, sore throat or blood in stools after the procedure. These are transient and should last about an hour. You are to notify us if you have continued blood in your bowel movements, high fever, worsening abdominal pain or vomiting.**

## SURGERY

The word Surgery is always very intimidating. Many of our patients, at the time of diagnosis, get worried that they will need surgery. That is not necessarily true. Only some patients with IBD need surgery. Indications for surgery are well defined and your Physician will discuss the reason for surgery, if needed. We will direct you on making appointments to a surgeon if necessary and we will stay in close communication with the surgical team regarding your care. We will introduce you to patients who have had surgery in the past if you request it.

We expect you to let us know your concerns about surgery and to let us know if you would like to meet other patients who have had surgery for their IBD.

### **Complications of IBD that may require surgery:**

- Intestinal obstruction (a blockage)
- Uncontrollable bleeding
- Stricture Formation (a narrowing of a section of the intestine)
- Formation of a fistula (an abnormal connection from the intestine to another part of the body)
- Formation of an abscess ( a collection of pus and inflammation)
- Perforation of the intestine (a tear or hole)

## Growth and Nutrition

You should expect us to refer you to a pediatric dietician at least yearly to share information with you related to nutrition and IBD. You should expect us to refer you to a growth specialist as needed.

We expect you to be honest about your eating habits and to make appropriate changes in your diet to improve your health.

From a dietary perspective there are a few questions which our patients usually ask.

1. **Are there any foods that cause IBD?** The answer is NO. As of today, no specific dietary factors have been proven to cause IBD.
2. **Is there a specific diet that will cure IBD?** The answer is NO. There is no scientific evidence that any food or diet can trigger a flare or cause remission. Some patients do not have problems with any food, while other patients perceive pain and diarrhea. We encourage the use of a food journal to determine food intolerances. It is important for you to let us know if you have eliminated entire categories of food out of your diet since this could cause caloric, vitamin and mineral deficiencies. There is no scientific study which has proven a curative diet for long term purposes. You will come across a number of books and web pages that talk about various diets that can fix IBD, but none of that work has been studied in a controlled environment without bias. Some of these diets can actually compromise your nutrition and therefore, you should consult your physician and dietitian before you start any specific diet.
3. **Is there a specific diet that can decrease my symptoms?** Yes. Low fiber and low residue diets are very important in patients with IBD. You may be surprised with this answer since typically we

advise a high fiber diet. In IBD we aim to decrease the residue, as high residue causes blockage in the terminal ileum and can increase the workload for an inflamed colon in patients with colitis.

4. **Do I need to increase my food or decrease my food intake?** The answer is Increase your daily intake. In IBD there is always some degree of malabsorption and therefore, the need to increase caloric intake. Additionally, because of the inflammation, caloric expenditure by the body is also increased. This results in the need to increase the amount of calories you ingest. However, it is important to also maintain a healthy weight for your body size.

## Adherence

Adherence means following the medical plan as prescribed. This means taking your medications daily and notifying us if you are having problems. Following your treatment plan should help you stay healthier and symptom-free. There are studies that show patients who do not take their medications as prescribed have a 30 to 40 percent greater chance of developing a flare. We understand that you lead a very busy life and it is easy to forget or miss a dose of medication. We want you to be honest with us about this so that together we can work on ways to keep you healthy.

### **Adherence Hints**

- Set an alarm on your cell phone as a reminder to take your medicine
- Look up [www.mymedschedule.com](http://www.mymedschedule.com) (This is a website that can send you reminder text messages or email alerts)
- Put medications in your home where you can see them.
- Leave yourself a note on the calendar or in a daily planner
- Keep a medication journal and check off when you take each dose. This will help you keep track of what you have taken so you do not miss a dose or take too many doses.
- Use a pill box and count out your medications for the whole week

## FINANCIAL RESOURCES

The diagnosis of a chronic illness can be overwhelming. It is very important for you to take initiative and learn what your insurance covers. You should check with your insurance company before you have tests done so that you are not left with enormous out of pocket expenses. Most insurance companies require prior authorization for CT Scans and MRIs. It is your responsibility to let us know if this is your situation and call the office so that we may get prior authorization in a timely manner. Please do not wait until the day before a test. Depending on your insurance company, this can be a very long process.

## Medications

Many of the medications prescribed to you have savings programs if you have conventional insurance. Lialda, Apriso and Asacol HD offer savings cards that can be given to you. Please call our office for a savings card, or ask for it during your appointment. Pentasa can be covered by Shire Cares if you meet certain financial guidelines. You can call our office and we will give you the necessary forms. There is a portion of the application that needs to be filled out by our office.

Remicade can be a very costly medication. Many insurance companies require prior authorization of this medication. It is important that you verify with our office that prior authorization was done before starting this medication. If you have conventional insurance, you may want to sign up for the Remistart program. This program helps defray the out of pocket expenses you pay for Remicade. It needs to be signed up for yearly and will help cover up to \$6000 per year. It will limit your cost to \$50/infusion for a total of 8 infusions. The program exhausts after 12 months, 8 infusions, or a maximum benefit of \$6000, whichever comes first. Please be aware that if you have a flexible spending account for health care,



and you fill out on the application that you will use it to cover your Remicade infusion costs, you will not qualify for the Remistart program.

## Lifestyle

Patients with IBD can live a normal life. You may go to college, play sports, work and participate in almost all activities. You can have normal romantic relationships and most people with IBD can have children since fertility is rarely affected.

School work can be difficult to handle when you are experiencing an IBD flare. All patients with IBD should have a 504 plan implemented to help with managing school. Please let us know if you need this.

Issues such as smoking and drinking alcohol should be discussed openly and honestly with your doctor. Smoking can affect both Crohn's and Colitis. Patients who smoke may not respond well to treatment, may have more frequent relapses and may have a higher risk for surgery. Therefore, it is best to never start smoking. If you do smoke, ask your doctor to direct you to resources to help you quit smoking. For patients who are of the legal drinking age, alcohol should never be consumed in excess. Many patients who drink alcohol experience worse IBD symptoms. Also, when taken with medications such as Flagyl, it can lead to severe nausea and vomiting.

## VACCINATIONS

Patients with IBD should receive their vaccinations on the recommended schedule except for live vaccines. This includes a yearly flu vaccine. The flu vaccine is particularly important since many IBD medications can slow down the immune system. This means that if you get the flu, it may be prolonged.

**The Important Things to Remember:** You should NOT receive live virus vaccines such as nasal flu-mist and the chickenpox vaccine if you are on any medications that would affect your immune system.

**All patients on Remicade, Humira or Cimzia need a yearly PPD skin test. It is important that you have your primary care physician fax us these results so we can have it in your chart.**

## DENTAL CARE

You should see your dentist on a regular basis. Medications used in Inflammatory Bowel Disease do not interfere with dental work and hence, any surgery required may be performed as needed.

## WEBSITE RESOURCES

The Children's Digestive Health and Nutrition Foundation (CDHNF)

- [www.cdhnf.org](http://www.cdhnf.org)

Crohn's and Colitis Foundation of America (CCFA)

- [www.ccfa.org](http://www.ccfa.org)

Gastro Kids

- [www.gastrokids.org](http://www.gastrokids.org)

Improve Care Now (part of our study)

- [www.improvecarenow.org](http://www.improvecarenow.org)

IBD University (IBDU)

- [www.ibdu.org](http://www.ibdu.org)