

# Treatments Options Summary

## What You Should Expect From Us

- Current information about available treatments
- Inform for potential side effects related to your therapy
- Discussion of treatment options, including which options your prefer

## What We Expect from You

- Follow treatment plans exactly as they are agreed upon and indicated
- Let us know if you have any concerns or problems with any part of your treatment plan
- Tell us if you are taking medicines other than those prescribed by your doctor (herbal or alternative medicines and supplements)
- Monitor for potential side effects related to your therapy
- Ask questions

## Why This is Important

Listed below are the most common medications as well as information on non-medication therapies such as nutritional support used to treat IBD in children, teens, and young adults. Before starting any treatments, please discuss them with your doctor or physician assistant. Following your treatment plan for IBD is extremely important. Changing your treatment plan without discussing it with your doctor or physician's assistant can be harmful. There are several suggestions offered in the "Adherence" section of this book that can help you remember to take your medications or follow any other prescribed protocol. There can be side effects from some medications when starting or stopping medications, always consult your doctor or physician's assistant. We check for side effects by doing blood tests and physical exams. That's why going to your clinic appointments and getting your blood tests done are so important!

## Medications Review:

### **Mesalamine**

Mesalamine is an aspirin-like medicine which helps control IBD. It can be taken by mouth or can be given by suppository or enema. The doses vary but it can require up to 3 times daily. Some examples of mesalamine products include: Asacol, Colazol, Pentasa, Canasa, Lialda, Apriso and Rowasa.

Rare side effects of these medications include allergic reactions, pancreatitis, and kidney injury. If you are taking these medications, you should wear sunscreen when outside to reduce the risk of skin rashes and sunburns.

### **6-mercaptopurine (6MP)/ Azathioprine**

These medications are immunosuppressants. Suppressing the immune system reduces inflammation in the GI tract. These medications do not work right away, so you may need to be on a combination of medications at first. It can be given by mouth.

Blood tests will be done regularly to check for possible side effects, including low white blood count and irritation of the liver or pancreas. Patients taking these medications should be

cautious about their amount of sun exposure. There is also a small increased risk for lymphoma (a tumor of the lymph glands) compared to the average person.

### **Methotrexate**

Methotrexate also suppresses the immune system. It can be given by injection (shot) or by mouth. Blood tests will be done often to check for potential side effects such as irritation of the liver and low white blood cell count. There is also a small risk of lymphoma.

### **Anti-Tumor Necrosis Factor or Biologic Medications**

These medicines include infliximab (Remicade), adalimumab (Humira), and others. They block the action of a protein in the body called TNF-alpha (tumor necrosis factor). TNF-alpha is made by the body's immune system. People with IBD may produce too much TNF-alpha which can cause inflammation.

Infliximab is given as an IV infusion and takes about 3 hours to infuse. The frequency of the infusions depends on your symptoms, but it is usually given every 8 weeks. Adalimumab is given by injection every 1-2 weeks. Before receiving any of these medications, your doctor will test you for tuberculosis.

You will have regular blood tests to monitor for possible side effects, including low white blood cell count, irritation of the liver, infections such as tuberculosis, and a small increased risk of lymphoma (a tumor of the lymph glands).

[Humira Savings \(Humira Complete\)](#) – Abbvie offers substantial savings for those using Humira. This program can save you thousands of dollars.

[Remicade Savings \(Remistart also known as Janssen Care Path\)](#) – Johnson & Johnson offers substantial savings for those using Remicade. Visit this link for enrollment information.

[Prescription Savings](#) – website that allows you to search the lowest cost per retailer in your area.

### **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. Because of this, it is important to take the medicine as prescribed and to slowly decrease the medicine as directed. Do not stop it without talking to your doctor. As the dose of prednisone is decreased, the body will slowly begin to make more natural hormones again.

Side effects of prednisone can include weight gain, hunger, and changes in mood and sleep patterns. These usually improve as the dose is lowered. Other side effects can include weakening of the bones, increased risk of infections, high blood pressure, high blood sugar, and stomach irritation. If you take prednisone or other corticosteroids, you should be up to date on vaccines, undergo regular eye exams, and may need to have bone density testing.

**Pregnant women or women planning to become pregnant should discuss treatment with your medical team.**

Resources:

[www.cdfa.org](http://www.cdfa.org) – Crohn’s and Colitis Foundation of America






[www.gikids.org](http://www.gikids.org) – NASPAGHAN Foundation

Videos:

[“Treatment 101”](#) – This video created by Crohn’s and Colitis Foundation of America explains the different types of medications.

[“107 - IBD School: Do I Have to Take Medications?”](#) - This video created by Michigan University explains the different types of medications.

[“Treating Moderate to Severe Ulcerative Colitis with Biologics”](#) - This video created by Healthline.com explains the use of biologic medications.

TREATMENT	Frequency	Taken by	Begin to Work in...	*Cost \$ / Generic✓	Side Effects		Cancer Risk	Keep in mind	
					Common	Uncommon		Avoid if...	Should Not...
<b>AMINOSALICYLATES</b>									
Sulfasalazine (Azulfine, Sulfazine)	3-4x/day	Mouth	2-8 wks	\$ / ✓	<ul style="list-style-type: none"> <li>Stomach upset</li> <li>Diarrhea</li> <li>Headache</li> <li>Cold symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Severe skin reaction</li> <li>Low blood counts</li> </ul>	No increase risk	TB	
Balsalazide (Colasal Giazol)	1-2x/day	Mouth	2-8 wks	\$ / ✓				TB	
Mesalamine (Pentasa, Delzicol, Row asa, Asacol, Lialda)	1-2x/day	Mouth/ Rectally	2-8 wks	\$ / ✓				TB	
<b>IMMUNOMODULATORS</b>									
6-MP (Purinethol, Purixan)	1x/day	Mouth	8-16 wks	\$\$ / ✓	<ul style="list-style-type: none"> <li>Mouth sores</li> <li>Nausea</li> <li>Stomach upset</li> <li>Cold symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Abdominal liver test</li> <li>Low blood counts</li> <li>Lung inflammation</li> </ul>	Possible risk		 live
Azathioprine (Imuran, Azasan)	1x/day	Mouth	8-16 wks	\$\$\$ / ✓				Possible risk	 live
Methotrexate (Otrexup, Rasuvo, Rheumatrex, Trexall)	1x/wk	Mouth/ Injection	4-6 wks	\$\$ / ✓				No increase risk	 live
<b>BIOLOGICS</b>									
Infliximab (Remicade)	Every 2 mos	Intravenous	2-12 wks	\$\$\$	<ul style="list-style-type: none"> <li>Common cold</li> <li>Sinus/throat infection</li> <li>Stomach upset</li> <li>Headache</li> <li>Allergic rash</li> <li>Local reaction</li> </ul>	<ul style="list-style-type: none"> <li>Psoriasis</li> <li>Lupus-like reaction</li> <li>Serious infection</li> <li>Low blood counts</li> <li>Developments of antibodies</li> <li>Muscle inflammation</li> </ul>	Possible risk	TB	live
Adalimumab (Humira)	Every 1-2 wks	Injection	2-12 wks	\$\$\$				TB	
Certolizumab (Cimzia)	Every 4 wks	Injection	2-12 wks	\$\$\$				TB	
Golimumab (Simponi)	Monthly	Injection	6-30 wks	\$\$\$				TB	
Vedolizumab (Entyvio)	Every 2 mos	Intravenous	2-52 wks	\$\$\$				TB	
<b>ENTERAL NUTRITION</b>									
Formula	Variable	Mouth/ NG tube	2-12 wks	\$ - \$\$\$	<ul style="list-style-type: none"> <li>Nausea</li> <li>Increase diarrhea</li> </ul>		No increase risk		Partial or complete 

\* Cost varies by insurance carrier deductibles and copays. However, this table indicates cost in general.

## **Other Treatment Plans Review:**

In addition to medications, there are other treatment options that may be discussed with you.

## **Enteral Therapy**

Enteral Nutrition Therapy is a total or partial liquid diet based on response. This may include taking your liquid diet by mouth or by a naso-gastric tube (a tube that delivers the formula directly into the stomach) or naso-jejunal tube (tube that delivers the formula directly into the intestine.)

Among dietary therapies, enteral nutrition has been studied the most. Instead of eating, all of a child's nutrition is met with a special drink or formula. Research has shown that these formulas are effective when taken as the sole source of nutrition. Recently, however, a study published by Children's Hospital of Philadelphia (CHOP) showed that enteral therapy may still be effective when a small amount of food is taken at the same time as a supplement.

Depending on the severity and location of the disease, enteral therapy as effective as steroids in children, and unlike steroids, there are virtually no side effects. This form of Crohn's treatment has many benefits, including improved growth and mucosal healing. The way enteral therapy works is unclear, but it may improve good bacteria in the gut, improve overall nutrition or eliminate an unknown dietary substance that causes an immune response. You will need to talk to your doctor and nutritionist to decide on the best formula for your child.

## **Sample Protocol**

- Induction: 80-90% of patient's caloric needs met using semi-elemental formula + normal diet as tolerated during the day. Continue x 8-12 weeks.
  - 10—20% of the diet comes from regular food
  - Your doctor or dietitian will calculate your calorie goals to determine your feeding regimen for home

## **Your Plan:**

\_\_\_\_\_ % calories from formula \_\_\_\_\_

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\_\_\_\_\_ % calories from food (regular diet) \_\_\_\_\_

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### How to calculate calories:

- Many apps are available – calorieking or myfitnesspal (both of these apps are available on the web)
- Read food labels and for calories and serving sizes
- Most restaurants have their calories listed on their menu or online

Suggested feeding regimen: \_\_\_\_\_

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Resources:

<https://700childrens.nationwidechildrens.org/treating-crohns-disease-nutrition-therapy/> - Nationwide Children's Hospital website provides information regarding Enteral Nutrition as a form of treatment.

[www.gikids.org](http://www.gikids.org) – NASPAGHAN Foundation has a podcast and information regarding Enteral Nutrition.

**Videos:**

[“Treating Crohn's Disease Without Medication”](#) – This video produced by Seattle Children's Hospital provides general information regarding Enteral Nutrition.

[NG Tube demonstration](#) - This video is an NG tube demonstration by an 8year old.

### **Specific Carbohydrate Diet**

The Specific Carbohydrate Diet (SCD) is a restricted diet that eliminates all grain, refined sugar and liquid milk. It does allow for honey as a sweetener and some fermented dairy. Currently our practice is conducting research on the effects of the SCD diet as a treatment option. The pilot research showed that this type of therapy is safe and successful option in place of medication on the small group of children.

Resources:

[www.breakingtheviciouscycle.info](http://www.breakingtheviciouscycle.info) – Breaking the Vicious Cycle website lays out the “ins” and “outs” of the Specific Carbohydrate Diet, recipes and general information about the history of the Specific Carbohydrate Diet.

[www.scdiet4kids.wordpress.com](http://www.scdiet4kids.wordpress.com) – Blog developed by an Atlanta mom to help those starting the Specific Carbohydrate diet.

[www.woodwardccf.com](http://www.woodwardccf.com) – Woodward Crohn's and Colitis Foundation started by an Atlanta mom to help fund nutritional research, share their Specific Carbohydrate Diet journey and help those starting the Specific Carbohydrate Diet.

[www.gikids.org](http://www.gikids.org) – NASPAGHAN Foundation has a podcast and information regarding the Specific Carbohydrate Diet.

**Videos:**

[“A New Path Through Diet for Crohn's and Colitis”](#) – this video produced by Children's Healthcare of Atlanta to encourage families understanding of why more research is needed for the Specific Carbohydrate Diet as well as seeing the Specific Carbohydrate Diet as a treatment option.

# Adherence

## What You Should Expect From Us

- Our understanding that you are doing your best to manage your condition according to your age and ability, which includes “adhering” to the treatment plan as agreed upon.
- A non-judgmental discussion of treatment adherence at every visit.
- Clear and simple instructions on how to take care of yourself including taking medications and eating the right diet for you.
- Tips to help you remember to take your medications or adhere to your diet.
- Possibly a referral to other resources or health care providers that can help you with adherence.

## What We Expect From You

- Follow the plan that your doctor, nurse practitioner, dietitian, and nurses have developed for managing your condition.
- Take your medications everyday as prescribed and get refills in a timely manner so that you do not run out.
- Let us know if thing(s) are getting in the way of taking the medications or maintaining your diet regiment (BE SPECIFIC – e.g., soccer practice).
- Manage your diet according to your registered dietitians or nutritionist’s recommendations
- Let us know when you have difficulties following the plan outlined by your healthcare team so that we can help.

## Why this is Important

Adherence means how well you follow the medical advice you are given (like taking medicine, making dietary changes, exercise). It has been proven that following your healthcare team’s instructions for managing your condition can help you stay healthier and symptom-free. Taking your medications is particularly important. Studies have shown that patients who do not take their medications have a 30 to 40 percent greater chance of experiencing a flare of their disease.

Many medications can be taken once or twice daily, but certain medications need to be taken more often. If you are on one of the medications that needs to be taken more often, you can talk to your doctor about trying to simplify your schedule. We realize that you are very busy with school, work, sports, and other activities and that it can be easy to “forget” or “miss” doses of your medications. In fact, it is very common for patients to miss doses, so you should not be worried about talking openly with your healthcare team about any problems you are having taking your medications. This is an important part of your care because good adherence is one of the best ways to stay healthy.

## Adherence Medication Hints

Here are a few helpful hints. They may help you remember to take your medications and to become more independent in managing your IBD.

- Set an alarm on your cell phone or watch as a reminder to take your medicine.
- Look up [www.mymedschedule.com](http://www.mymedschedule.com) (a web site that can send you reminder text messages or e-mail alerts).
- Other apps are available such as: Medi-Prompt, Pill Alert Pro, Easy Pill, Medication Log
- Put medications where you can see them (ex. next to toothbrush or in the kitchen). Include your medications as part of your daily routine. Fit them into your life instead of rearranging your life around them.

- Leave yourself a note on the refrigerator or bathroom mirror (ex. "Take vitamins with dinner!"), on a calendar or in a daily planner.
- Keep a medication journal and check off when you take each dose. See below.
- This will help you keep track of what you have taken so you don't miss doses or take too many doses.
- Stay organized – Use pill boxes and count out your medications for the whole week.
- Ask for help – Mom, Dad, and other family members can help you remember to take your medications. Take on more responsibility as you get older, but recognize when you need help and ask for it.

### **Adherence Enteral Nutrition Hints**

- Ask for help - Connect with other parents or patients that are on the enteral nutrition so they can provide support or answer questions.
- Watch demonstration video (link provided previously).
- As a parent, you can actually demonstrate and insert NG tube into your nose to show your child.
- Pretending to feed a stuffed animal can be helpful for younger kids.
- Stay organized.
- Set a bedtime routine if necessary to allow sufficient time for the process

### **Adherence Specific Carbohydrate Diet Hints**

- Learn about the Diet and take it one step at a time.
- Plan your weekly menu so you can prep your meals during the weekend when you have more time.
- Ask for help - Connect with other parents or patients that are on the SCD so they can provide support or answer questions on food preparation.
- Stay organized and plan ahead for social gatherings.
- Always have food with you in case you get hungry to prevent temptation from eating food that you are not supposed to.
- Use a journal to log your menu to help you track any symptoms that might arise.





