



Kids deserve the best.

IBD NEW DIAGNOSIS EDUCATION CHECKLIST

(Provider)

Below is an outline of the major areas that should be covered during a new diagnosis teaching visit along with available supplemental material for patients in *italics*, **BOLDED** should be in folder.

1. IBD Basics
 - Crohn's vs. UC
 - Extent of disease
 - *IBD CARTOON: CARTOONGI.COM*
 - *CCFA: The Facts About Inflammatory Bowel Disease*

2. Testing for IBD
 - Endoscopy/Colonoscopy
 - Small bowel imaging
 - Blood work
 - i. Inflammatory markers
 - ii. Varicella/Hepatitis/TB
 - iii. TPMT genetics
 - iv. Nutritional labs
 - DEXA scan

3. Medications and other therapies
 - Med choices and rationale
 - Nutritional therapy
 - Surgery
 - Plan for ongoing monitoring
 - Multivitamin
 - **IBD MEDICATIONS**
 - **CCFA: Immunizations**
 - *CCFA: Understanding IBD Medications and Side Effects*
 - *NASPGHAN Video: myemmi.com/SelfReg/DECIDEIBD*

4. Support
 - Online resources
 - ImproveCareNow
 - Counseling services
 - Dietitian
 - School
 - **ADDITIONAL RESOURCES**
 - *504 LETTER (EPIC: ".IBD504")*
 - **CCFA: School Accommodation (504)**
 - **CCFA: IBD Insurance Checklist**
 - *CCFA: IBD & ME Activity Book (for ages 8-12)*
 - *CCFA: Guide for Teens with IBD*
 - *CCFA: Young Adults*
 - *CCFA: Women*
 - *CCFA: Guide for Teachers and Other School Personnel*
 - **WHEN TO CALL**

5. Who to call and when to call
 - External order as needed for action plan

6. MyChart

PLEASE USE SMARTPHRASE ".IBDTEACHING" IN EPIC TO DOCUMENT WHICH TOPICS YOU COVERED AND RESOURCES GIVEN TO PATIENT.

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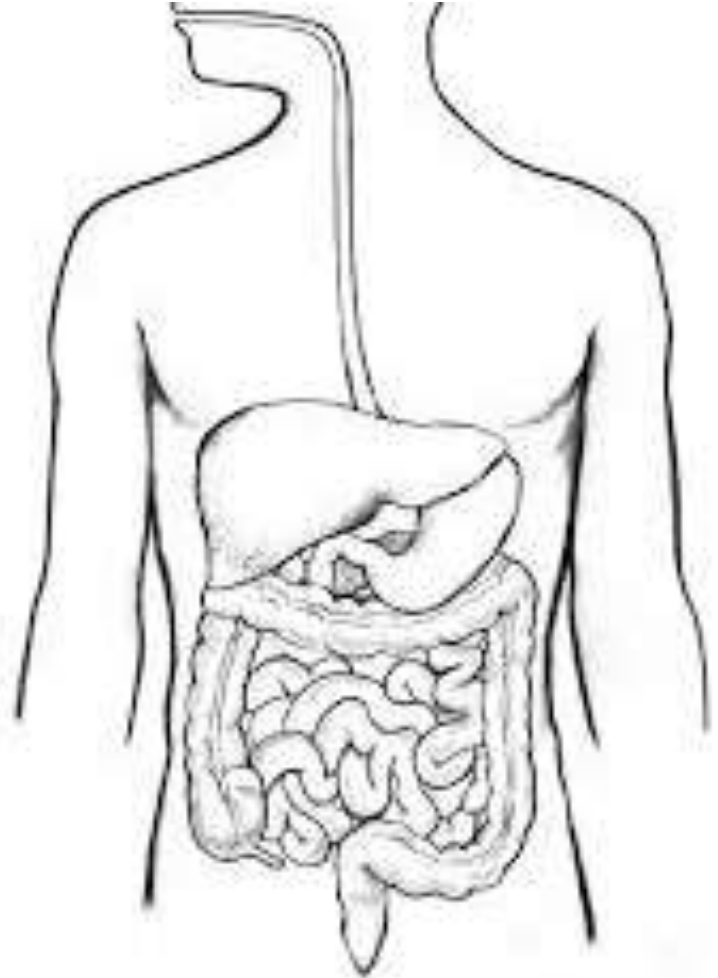
(Patient)

I understand the basics of Inflammatory Bowel Disease

- I have:
 - *Crohn's disease*
 - *Ulcerative Colitis*
 - *Indeterminate Colitis*

○ My disease is located:

- Esophagus
- Stomach
- Duodenum
- Jejunum
- Ileum
- Colon
 - Total colon
 - Right colon
 - Transverse colon
 - Left colon
 - Sigmoid colon
 - Rectum



I understand the tests that have been done and which ones I will need in the future:

- Endoscopy and Colonoscopy: Date _____
- Small bowel imaging: Type: _____ Date _____
- Blood work
 - Inflammatory markers
 - Varicella/Hepatitis/TB
 - Drug metabolism testing
 - Nutritional labs

I understand the different ways to treat IBD and which method is best for me at this time

- Handout: IBD Medications

I know where I can find more information about IBD and where I can get extra support to help me cope with this illness

- Handout: Additional Resources
- I know who to call and when to call
 - Handout: When to Call and IBD action plan
- I understand the importance of nutrition in my disease
 - Handout: Nutrition in Inflammatory Bowel Disease
- I have the resources I need for school (excuse note, letter for accommodations- 504 plan)
- I have the resources I need for medications and office visits
- I have signed up for MyChart so I can monitor my labs and contact my doctor at any time via e-mail

IBD Medications

Check out ibdmedicationguide.org for an interactive guide on all the medications below

Medication Class	Mechanism	Generic Name	Selected Brand Name(s)	Usual Route	Treatment Frequency	Immune Suppression	Starts to Work **
Nutrition Therapy	Microbiome and nutrition	Many brand names	Pediasure, Boost, Ensure...	Oral or feeding tube	Daily x 12 weeks	No	1 – 3 weeks
Aminosalicylates	Anti-inflammatory topical therapy	Sulfasalazine	Azulfidine	Oral	2-3x / day	No	1 week
		Balsalazide	Colazal	Oral	1-2x / day	No	
		Mesalamine	Apriso, Asacol HD, Delzicol, Lialda, Pentasa	Oral	1-2x / day	No	
			Canasa	Suppository	1-2x / day	No	
			Rowasa	Enema	1-2x / day	No	
Corticosteroids	Anti-inflammatory	Budesonide	Entocort EC, Uceris	Oral	1-2x / day	No	3-5 days, Not for long term use
		Prednisone	Deltasone	Oral	1x / day	Yes	
		Prednisolone	Orapred, Prelone, Pediapred	Oral	1-2x / day	Yes	
		Hydrocortisone	Cortifoam	Rectal Foam	1-2x / day	No	
			Anusol HC	Suppository	1-2x / day	No	
Immune modulators	Resembles “ingredient” needed for cells to replicate	Azathioprine	Imuran	Oral	Nightly	Yes	Around 8 weeks
		6MP, mercaptopurine	Purinethol	Oral	Nightly	Yes	
		Methotrexate	Rheumatrex	Oral or Injection	1 x / week	Yes	
Biologics	Anti-TNF (Tumor Necrosis Factor)	Infliximab	Remicade, Renflexis, Inflectra, Avsola, Ixifi	Infusion	Every 6 – 8 weeks	Yes	Varies
		Adalimumab	Humira, Cyltezo, Amjevita	Injection	Every 1 – 2 weeks	Yes	
		Certolizumab	Cimzia	Injection	Every 4 weeks	Yes	
		Golimumab	Simponi	Injection	Monthly	Yes	
	Anti $\alpha 4\beta 7$ -integrin Stops immune cells from exiting gut vessels	Vedolizumab	Entyvio	Infusion	Every 2 months	Local	
Anti-IL12/23 Stops interleukin signal	Ustekinumab	Stelara	Injection	Every 2 months	Yes		
Antibiotics	Antibiotic and microbiome modification	Metronidazole	Flagyl	Oral	2 x / day	No	24 – 72 hours
		Ciprofloxacin	Cipro, Proquin	Oral	2 x / day	No	

** Every patient responds differently to medication and may take longer time to respond. This is just a guideline. **



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When to Contact

Please call if you/your child has any of the following symptoms:

1. Temperature above 101 for two days
Especially if on Prednisone, biologic or immune modulator and have no other explanation for fever
2. Stomach pain/cramps worse than usual and doesn't go away
3. More than the usual bowel movements in a day or change in stool consistency
4. Waking up at night to have bowel movements
5. Blood (red or dark black) in bowel movements or an increase in the amount of blood
6. New pain around the anus or in rectum or new skin tags
7. Vomit with bile (green color)
8. Fatigue that doesn't go away
9. Rashes – especially on the lower legs
10. Swelling or pain in the joints
11. Changes in vision, eye pain
12. For patients with Ulcerative Colitis or IBD-U: If there is a Pediatric Ulcerative Colitis Activity Index (PUCAI) score above 35

You know your child the best.

If for any reason you are concerned, please call or contact via MyChart:

M-F 8:00AM – 4:00PM: Call _____

MyChart messages allow you to send photos if needed.

Overnight and on weekends:

Call 414-266-2000 and ask to speak to GI fellow on call



ADDITIONAL RESOURCES

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Crohn's and Colitis Foundation	crohnscolitisfoundation.org or 1-800-932-2423	Information about inflammatory bowel disease and support services for children and families
Wisconsin Crohn's and Colitis Foundation Chapter	crohnscolitisfoundation.org/chapters/wisconsin/ or 414-465-5520	Local Wisconsin chapter
CartoonGI	moviegi.com	Website with various child friendly cartoons explaining endoscopy and IBD.
Doc4Me	doc4me-app.com	Transition app for patients with IBD listing adult IBD providers around the United States. Available for android and iOS.
Just Like Me	justlikemeibd.org	Website for Teens with IBD
Power of Two	crohnscolitisfoundation.org/power-two	Support program matching individual mentors and mentees who want to talk by phone, email, or Skype to other patients and caregivers with IBD. The aim is to match people facing similar experiences or concerns. <i>*Please note that this is not an emergency service and matches are typically made within one to two weeks.*</i>
Camp Oasis	crohnscolitisfoundation.org/get-involved/camp-oasis	Weeklong summer camp for children in grades 2-12 with IBD. Participate in camp activities (boating, swimming, arts & crafts, ropes course, and special events) with 24 hour on-site physicians, nurses, and other healthcare professionals
Smart Patients	smartpatients.com	An online community for patients and families affected by a variety of illnesses. Learn at your own level about scientific developments related to your condition, share your questions and concerns with other members, and use what you learn in the context of your own life.
ImproveCareNow (ICN)	improvecarenow.org/patients-parents ANY family at our center can join the parent working Group via: improvecarenow.org/parent_working_group_signup	A learning healthcare network for children with Crohn's disease and ulcerative colitis. The parent working group is comprised of parents across the United States who all care for children with IBD. The ICN Parent Working Group features monthly webinars and newsletters which provide information and resources from across the network.

Mental Health/Coping:

We advise you to reach out to your IBD team or to your primary care provider to obtain the most up to date list of counseling services which work in your community and with your insurance plan.

Medication Assistance:

A Note on Biosimilars - There are a number of biosimilars frequently being released. These are similar to a generic medication but from the biological class of drugs. All of these medications are basically the same in effect. Each insurance plan may dictate which one we choose. We advise and prescribe based on your child's need and the best fit for their particular disease extent, but are not able to dictate which particular medication brand versus generic (biosimilar) is chosen.

Infusion name	Assistance Program Name	Website
<u>Remicade infusions</u>	Remistart program	remicade.janssencarepathsavings.com
<u>Inflectra infusions</u>	Pfizer Encompass program	pfizerencompass.com
<u>Renflexis infusions</u>	Merck Access program	merckaccessprogram-renflexis.com
<u>Avsola infusions</u>	Amgen Assist	avsola.com/HCP/support-and-resources
<u>Humira injections</u>	Humira complete	humira.com/humira-complete/cost-and-copay
<u>Entyvio infusions</u>	Entyvio Connect	entyviohcp.com/connect
<u>Cimzia injections</u>	Cimzia Cimplicity	cimzia.com/signup
<u>Symponi injections</u>	Janssen Carepath	janssencarepath.com/patient/simponi/cost-support
<u>Stelara injections</u>	Janssen Carepath	stelarainfo.com/crohns-disease/cost-support-and-more



The IBD Team

Kids deserve the best.

- IBD Provider: _____ / _____
- Nurse: _____ Ext: _____
- Dietitian: _____
- Psychologist: _____

About our team: Because Children's Hospital of Wisconsin is an academic hospital you may meet a number of other people caring for you in clinic or while an inpatient. These may include:

– *Attending Physician:* Oversees your care and is board certified in pediatric gastroenterology. An attending has completed 4 years of medical school, 3 years of pediatric residency, and 3 years of pediatric gastroenterology fellowship. When admitted, you may be cared for by an attending who is not your primary GI physician. Your primary GI will always get updates about your care and help make important decisions.

– *Nurse Practitioner:* A nurse who has completed additional training to care and manage patients under the supervision of a physician. You may meet with a nurse practitioner when your disease is under control, and they will be able to see you with more flexible schedules than your primary GI doctor. A nurse practitioner practicing in IBD care will have expertise in managing patients with IBD and will not make big or important decisions without consulting a GI physician.

– *Pediatric GI Fellow:* Completed pediatric training and is training in pediatric gastroenterology. They work closely with the residents, nurses, and attending physicians.

– *Pediatric Residents:* Completed medical school and are training in pediatrics. They are supervised by the attending physician and fellow. There are residents in the hospital 24 hours a day and are first contact while inpatient.

– *Medical students:* In training to be doctors. Supervised by the residents and the attending physician.

– *Nurses:* Office nurses answer phone calls, help with supplies, and do prior authorizations and teaching. Inpatient nurses provide bedside care.

– *Dietitian:* You may meet a dietitian during your first visit and as needed for future visits. The dietitian helps with nutrition supplements, makes sure your body is getting all of the nutrition it needs and can guide your dietary choices when following a restrictive diet.

– *Social Worker:* Hospital social workers can help with financial, insurance, community resource guidance, psycho-social support, and addressing transportation barriers to care.

– *Research Coordinator:* You may meet a research coordinator during a visit to the clinic or if you are in the hospital. The research coordinator helps enroll patients in research projects that are ongoing at the hospital and collect data for patients that are enrolled. They work closely with the doctors but ensure that participation in research does not affect your care.

Daily iron requirements for children and teenagers varies based on age, gender, and disease activity. Your doctor will help you decide how much iron you need.

Pediatric Ulcerative Colitis Activity Index

1. Each category should have a single score. Write each category's score based on symptoms from the last 48 hours on the line to the right. If you are undecided between two scores in a category, pick the higher score.
2. Add all those written numbers together and place that total under "**Total Score**"

Symptoms		Score
1. Abdominal Pain		
No Pain	0	
Pain can be ignored	5	_____
Pain cannot be ignored	10	
2. Rectal Bleeding		
None	0	
Small amount only in less than half the stools	10	
Small amount with most stools	20	_____
Large amount, with >50% of the stool content	30	
3. Stools Consistency of Most Stools		
Formed	0	
Partially Formed	5	_____
Completely Unformed	10	
4. Number of stools in 24 hours		
0-2	0	
3-5	5	_____
6-8	10	
Greater than 8	15	
5. Nighttime stools that wake the patient up		
No	0	_____
Yes	10	
6. Activity Level		
No limitation of activity	0	_____
Occasional limitation of activity	5	
Severe Restricted Activity	10	
Total Score		_____