



Importance of Decision-Making and My Child's IBD Treatment

A Helpful Tool for Parents
and Pediatric Caregivers



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Taking an active role in your child's healthcare

When children are diagnosed with inflammatory bowel diseases (IBD), there is a lot to learn, and often, there are a lot of decisions to be made.

For younger children, family members may play an important role in helping to make decisions with the healthcare team. As children get older and become adults, they will likely work more independently with their healthcare providers to manage their Crohn's disease or ulcerative colitis.

This guide provides information and tools to empower your family to take an active role in decision-making about your child's health. Both your and your child's thoughts, opinions, questions, and concerns are important! Voicing them will help your child's doctor provide the best care possible.

The Crohn's & Colitis Foundation provides information for educational purposes only. We encourage you to review this educational material with your healthcare professional. The Foundation does not provide medical or other healthcare opinions or services. The inclusion of another organization's resources or referral to another organization does not represent an endorsement of a particular individual, group, company, or product.

Importance of patient participation in healthcare decision-making

There are lots of different treatment options for Crohn's disease and ulcerative colitis. Learning about them may be confusing, overwhelming, and sometimes even scary.

There are many sources for information about treatments, and some are more accurate than others. It's important to get information from a source that includes both scientific research to back up ideas along with pros and cons of treatments. There's no one treatment that is right for every patient. It's important to understand the options available to your loved one and think about which one will fit best into their life.

Shared decision-making—when doctors, patients and families work together to pick the best treatment—has been shown to help patients be happier with their choices, know more about their disease, and be better at taking their medication as prescribed.^{1,2}



TIP:

Remember that your child's doctor is a great source for information about taking care of your child's health! If you have questions and are looking for resources, be sure to include a conversation with your healthcare team.

Additional resources:

- **Crohn's & Colitis Foundation's IBD Help Center**

Whether you're looking for a specific resource, referrals to other organizations, or answers to questions you can't find anywhere else, you can speak with helpful specialists at the Crohn's & Colitis Foundation's Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center), Monday through Friday, 9:00 am to 5:00 pm EST. 888-MY-GUT-PAIN (888-694-8872); info@crohnscolitisfoundation.org

- **Emmi Treatment Options for Pediatric Crohn's: A Guide for Patients and Families (NASPGHAN Foundation)**

Emmi programs are web-based presentations that take complex medical information and make it easy for you and your family to understand. You can view these programs online and share them with your friends and family. <https://www.my-emmi.com/SelfReg/DECIDEIBD>

You may also find a suite of decision resources on the Crohn's & Colitis Foundation website at www.crohnscolitisfoundation.org



Treatment overview

Learning about and understanding medication options will help you to make informed decisions with your healthcare provider.

Because Crohn's disease and ulcerative colitis can flare up after an initial remission (period in which symptoms disappear or decrease), the goal of treatment is to achieve and maintain remission. There are certain treatments that are used to induce remission and others that are used to maintain remission. Sometimes the choice of treatment also depends on how severe the disease is.

	Crohn's Disease	Ulcerative Colitis
Induce Remission	Biologics Corticosteroids Nutritional therapy	Aminosalicylates Biologics Corticosteroids Janus kinase inhibitors
Maintain Remission	Biologics Immunomodulators	Aminosalicylates Biologics Immunomodulators (Azathioprine and 6MP) Janus kinase inhibitors

Treatments can include medication, nutritional therapies, or surgery. Not every treatment is successful for every person, and unfortunately, sometimes a treatment can work for a while and then lose effectiveness. The goal is to find a treatment that works, and to continue to use it for as long as it is effective and well tolerated. When the treatment is working well, your child should not have any symptoms and should be able to do all usual day-to-day activities.

This table provides an overview and highlights some of the benefits and potential risks of treatments. We encourage you to review this educational material with your child's healthcare professional.

Prescription Medication			
Treatment	Overview	Benefits	Potential Risks
Aminosalicylates	<p>What: Anti-inflammatory</p> <p>How: Can be given orally or rectally</p> <p>How often: Daily (once, twice, or up to four times a day)</p> <p>Examples: balsalazide (Colazal®), mesalamine (Apriso®, Asacol®, Canasa®, Delzicol®, Lialda®, Mezavant®, Pentasa®, Rowasa®, Salofalk®), sulfasalazine (Azulfidine®)</p>	<ul style="list-style-type: none"> • Can lead to and keep ulcerative colitis patients in remission • Safe, well tolerated, with minimal side effects 	<ul style="list-style-type: none"> • Nausea/vomiting • Headache • Pancreatitis • Worsening colitis • Kidney inflammation

Prescription Medication			
Treatment	Overview	Benefits	Potential Risks
Biologic/biosimilar therapies	<p>What: Large molecules (antibodies) that target and bind to molecules in the immune system to block mediators of inflammation (i.e., molecules that alter one of the immune pathways to decrease inflammation)</p> <p>How: Can be given through an IV or as an injection</p> <p>How often: Every 2, 4, or 8 weeks (depending on the medication)</p> <p>Examples: adalimumab (Humira®), adalimumab-abdn (Cyltezo™), adalimumab-atto (Amjevita™), infliximab (Remicade®), infliximab-abda (Renflexis®), infliximab-dyyb (Inflectra™), infliximab-qbtx (IFIXI™), ustekinumab (Stelara®), vedolizumab (Entyvio®)</p>	<ul style="list-style-type: none"> • Effective in getting patients into remission and keeping them in remission • Helps to heal the lining of the gut, bringing it back to normal appearance • Used in fistulae treatment 	<ul style="list-style-type: none"> • Increased risk of infections (viral, bacterial and fungal) • Reactivation of previous infection: Hepatitis B and tuberculosis • Infusion reactions • Injection site pain • Psoriasis • Lupus-like reaction • Skin cancer • Fatigue, headache, malaise in the one to two days after taking it • NO risk of lymphoma when taken on its own
Corticosteroids	<p>What: Medication that helps to decrease inflammation</p> <p>How: Can be given orally, rectally, or by IV</p> <p>How often: Daily</p> <p>Examples: budesonide (Entocort® and Uceris™/Cortiment®), methylprednisolone (A-Methapred®, Depo-Medrol®, Medrol Dosepak®, Solu-Medrol®), prednisolone (Oraped®, Prelone®, and Pediapred®), prednisone (Deltasone®)</p>	<ul style="list-style-type: none"> • Works quickly (within days) to help patients feel better by decreasing swelling and inflammation 	<ul style="list-style-type: none"> • Suppresses immune system—increased risk of infection • Decreased bone density • Increased appetite and weight • Facial swelling • Acne • Stretch marks • Difficulty sleeping • Increased blood sugar • Increased blood pressure • Suppresses the adrenal glands • Muscle pain • Mood changes • Growth failure • Impaired wound healing • Rare—decreased blood flow to the hip bones (avascular necrosis) <p><i>*Most side effects are reversible when the medication is stopped</i></p>

Immunomodulators	<p>What: Medication that alters the immune response to help decrease inflammation</p> <p>How: Can be given orally (azathioprine, 6-MP, and methotrexate) or injected (methotrexate)</p> <p>How often: Daily (azathioprine and 6-MP) or once weekly (methotrexate)</p> <p>Examples: azathioprine (Azasan®, Imuran®), 6-MP/mercaptopurine (Purinethol®), methotrexate (Rheumatrex®)</p>	<ul style="list-style-type: none"> • Used to keep patients in remission and therefore decrease need for steroids or for hospitalization and surgery 	<ul style="list-style-type: none"> • Increased risk of infection, especially viruses <p>Azathioprine:</p> <ul style="list-style-type: none"> • Decreased blood counts • Pancreatitis • Liver injury • Lymphoma • Skin cancer <p>Methotrexate:</p> <ul style="list-style-type: none"> • Decreased blood counts • Liver injury • Nausea/vomiting
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Janus Kinase inhibitors (JAK inhibitors)	<p>What: Medication that blocks pathways of inflammation</p> <p>How: Given orally</p> <p>Examples: tofacitinib (Xeljanz®)</p>	<ul style="list-style-type: none"> • JAK inhibitors are currently FDA-approved to treat ulcerative colitis in adult patients • Some providers have started using the JAK inhibitors off-label in children; experience is increasing
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Nutrition Therapy

Treatment	Overview	Benefits	Potential Risks
Enteral nutrition; through nasogastric (NG) tube or consumed orally	<p>What: Formula that delivers nutrients to the stomach</p> <p>How: Can be given through a tube in the nose that goes into the stomach, or can be consumed by mouth (drinking it)</p> <p>How often: Daily for approximately 6-8 weeks</p>	<ul style="list-style-type: none"> • Effective in getting patients into remission • Improves nutritional status and avoids steroid use • Safe, well tolerated, with minimal side effects 	<ul style="list-style-type: none"> • Diarrhea • Brief discomfort from the tube • Unable to eat solid foods while on exclusive nutritional therapy, but can drink clear liquids

Surgery

Treatment	Overview	Benefits	Potential Risks
Surgery for Crohn's disease	<p>What: Removal of the part of the bowel that has inflammation, is narrowed/strictured, or has fistulae which may have caused an abdominal abscess</p>	<ul style="list-style-type: none"> • Removing the diseased area can help a patient go into remission 	<ul style="list-style-type: none"> • Surgery complications (infection, leakage)
Surgery for ulcerative colitis	<p>What: Removal of the colon (either creating an ostomy to the skin, or re-connecting the bowel by attaching the small bowel to the rectum called a pouch)</p>	<ul style="list-style-type: none"> • Removing the colon can decrease or even eliminate need for medications in some patients 	<ul style="list-style-type: none"> • Inflammation in the pouch with associated diarrhea and bleeding

*Talk to your doctor about other types of surgery for Crohn's disease and ulcerative colitis.



TIP:

There are many therapies currently under investigation—for a current, up-to-date list of all FDA-approved medications for Crohn’s disease and ulcerative colitis, please visit the Foundation’s online IBD Medication guide: www.ibdmedicationguide.org. Additional information is available in our Understanding IBD Medications and Side Effects brochure at www.crohnscolitisfoundation.org/brochures

Considering risks and benefits

All medications you take, even ones thought of as relatively safe like over-the-counter acetaminophen, can have risks and benefits.

What your family and your healthcare team need to decide together is what medicine will provide the most benefit, despite the risks. Some potential risks can be difficult to think about, but understanding what the risk really means and how much the medicine can help your child (benefits) is important to help you make treatment decisions. Keep in mind that there is also risk associated with under treating or not treating IBD.

Here’s an example: the risk of getting into a major car accident is 10 in 100,000. Does this keep you from getting in your car every day to get to work or school? Probably not! Because the vast benefit that comes from driving in your life likely outweighs the very small risk of a major car accident.

Thinking about treatment goals, values, and fears

When deciding on which treatment is best for your child, it’s important to think about what is important to your family. What matters most may be related to how your child takes medication (by mouth versus through a vein), whether you’re open to a dietary treatment for IBD, or what long-term problems worry you most. For example, for some people, not taking pills is a big goal, so a medicine given through a vein is a better choice. For other people, avoiding certain medication side effects is more important, so they may try a special diet to treat their IBD. Without knowing about your family’s goals, values, and fears, your doctor won’t be able to help you choose the best treatment for your child.

Together with your child, discuss treatment goals, values, and fears. Complete this worksheet and bring it to your next doctor’s visit.

Treatment goals, values, and fears worksheet

In each section, choose from the examples or come up with your own.

Treatment Goals	
What are your treatment goals?	Examples: reduce symptoms and feel better; achieve long term remission; avoid surgery; participate in daily activities 1. _____ 2. _____ 3. _____
Treatment Values	
What treatment characteristics are important to you?	Examples: administered in the hospital or at home; how treatment is administered (IV, injection, oral); effectiveness; side effects; how often treatment is needed 1. _____ 2. _____ 3. _____ 4. _____ 5. _____
Treatment Fears	
What makes you feel unsure or afraid?	Examples: treatment will affect my ability to participate in school or activities; cost of treatment; not understanding what a treatment is doing to my body; risk of side effects; pain with injections 1. _____ 2. _____ 3. _____ 4. _____ 5. _____
Take Action!	
What are your next steps?	<input type="checkbox"/> Talk as a family about treatment goals, values, and fears. <input type="checkbox"/> Talk with your healthcare team about treatment goals, values, and fears. <input type="checkbox"/> Write down your questions and share them at your next visit. Questions: 1. _____ 2. _____ 3. _____ 4. _____

Communicating with the healthcare team

Discuss any concerns you have about your child's symptoms or treatments with their healthcare team, and encourage and support your child to do the same. Their healthcare providers want to know what you are thinking and what you are worried about to be able to address these issues and make the best choice possible.

It may be helpful to make a list of questions at the time you think of them to bring to your appointment. It can be hard to remember everything you'd like to ask when you walk into clinic.

Your child's healthcare team is your partner in managing their IBD. Communicate regularly with them about how your child is feeling. Keep in mind that new research is being done all the time. Keep the conversation about treatment going to make sure their choice continues to be right for your child.

Additional resources

- Justlikemeibd.org—visit the Just Like Me IBD website for treatment information for teens addressing medications, tests, surgery, nutrition, and research
- To access the Foundation's resources, visit www.crohnscolitisfoundation.org/brochures
 - Recently Approved Treatments
 - Understanding IBD Medications and Side Effects
 - Clinical Trials FAQs
 - Aminosalicylates
 - Antibiotics
 - Biologics/Biosimilars
 - Corticosteroids
 - Immunomodulators
 - JAK Inhibitors
 - Surgery

References

¹ Brinkman WB, Hartl Majcher J, Poling LM, et al. Shared decision-making to improve attention-deficit hyperactivity disorder care. *Patient Educ Couns*. 2013;93(1):95-101.

² Wilson SR, Strub P, Buist AS, et al. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American journal of respiratory and critical care medicine*. 2010;181(6):566-577.

About the Crohn's & Colitis Foundation

The Crohn's & Colitis Foundation is the largest non-profit, voluntary, health organization dedicated to finding cures for inflammatory bowel diseases (IBD). The Foundation's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults who are affected by these diseases.

The Foundation works to fulfill its mission by funding research; providing educational resources for patients and their families, medical professionals, and the public; and furnishing supportive services for those afflicted with IBD.

We can help! Contact us at:

888-MY-GUT-PAIN

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Questions?

Contact the IBD Help Center
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