



**CIRCLE OF CARE:
A GUIDEBOOK FOR CAREGIVERS
OF CHILDREN AND ADOLESCENTS
MANAGING CROHN'S DISEASE**



WITH SUPPORT FROM THE
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FOREWORD

Crohn's disease (CD) impacts many millions of people globally, and is becoming more common, particularly in the developing world. While this debilitating condition can occur at any age, approximately 25% of cases are diagnosed before adulthood. Children and adolescents with Crohn's disease deserve particular attention, as they often develop more severe disease, and have more specialized needs, in comparison with adults. Without an adequate support system or the appropriate resources, young patients are put at a severe disadvantage in adulthood.

Many children and adolescents rely on the support of family or friends acting as their caregivers. Caregivers assist with a wide variety of tasks that children and adolescents would not be able to accomplish on their own, such as finding and securing access to treatment and resources, performing medical and nursing tasks, helping to plan and manage dietary and nutrition strategies, and providing transportation to medical appointments. In addition, caregivers must deal with the personal and financial demands of their role, from demands on their time that may conflict with work, to managing healthcare costs and insurance.

The mission of the Helmsley Charitable Trust's Crohn's Disease Program is to address the unmet needs of people living with the disease, investing in research and technologies that will improve care and treatment for patients, and finding a cure. We recognize the important role played by caregivers in supporting children and adolescents with Crohn's disease through their daily healthcare journeys, and are honored to support the National Alliance for Caregiving in producing this Guidebook. This compendium of informed guidance and pragmatic resources fills an important need for caregivers of children and adolescents living with Crohn's disease, and we hope that it will help members of this unpaid and underacknowledged workforce to continue to advocate for and support the young patients in their care.

Paul Scholl
Crohn's Disease Program Director

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The National Alliance for Caregiving is proud to present *Circle of Care: A Guidebook for Caregivers of Children and Adolescents Managing Crohn's Disease*. This guidebook was made possible through the generous support of The Leona M. and Harry B. Helmsley Charitable Trust, as well as through the contributions and direction of the following authors in caregiving and mental health.

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TABLE OF CONTENTS

2	Foreword
3	Acknowledgements
4	Welcome
5	Introduction
7	Caring for a Child or Adolescent with Crohn's Disease
15	Healthcare
16	Getting Acquainted with Crohn's Disease
20	Understanding Symptoms, Flare-ups & Remission
24	Understanding & Advocating for Various Medications, Therapies & Surgery for Your Child
32	When Something Doesn't Go as Planned
34	Health Maintenance, Supplementation, & Vaccination
39	Cost of Care & Access
42	Care Coordination, Medical Tasks, Activities of Daily Living
50	Empowering Your Child to Manage Their Crohn's Disease
51	Talking to Your Child About IBD
52	Managing Care Transitions
53	Empowering Your Child to Be Safe & Independent
55	Food and Nutrition
57	Teaching Your Child Self-Care Strategies
57	Empowering Your Child to Have Meaningful Relationships
59	Managing Difficult Conversations with Your Child
60	Caring For Yourself & Your Family
61	Family Relationships
62	Extended Family, Friends, and Other Social Interactions
64	Spirituality
65	Respite
65	Balancing Work & Care
67	Resources
71	Glossary

WELCOME

Hello and welcome to this journey called Crohn's disease. My name is Ellen and I am a care partner with my daughter who lives with Inflammatory bowel disease.¹ You may be thinking, what is a care partner? Well, my daughter is 18 years old and she has become more independent in taking charge of her medical and emotional care, while I continue to offer her guidance and support. My caregiving journey started when she was a young teen and newly diagnosed with severe disease. Teen years are formidable at best, add chronic disease and we found ourselves dealing with challenges and battles on many different fronts. This feeling was quite daunting to each of us at first. We somehow each found courage and inner strength to push through. We didn't do this alone. We had the support of our GI² and emotional health teams to guide and support each of us. I don't have IBD so why do I say we and us? Well, this is my journey, too, as a caregiver. It's a difficult task on top of an already demanding job of juggling parenting, managing a household and a job, along with my own physical and emotional health. So, yes, this is my journey, too, and yours, as well. You are not alone.

This guidebook contains resources for caregivers and pediatric patients. There are not a lot of resources out there specifically for pediatric Crohn's patients, which makes this guidebook such a valuable tool to have. You don't need to read this guidebook all at once. Go to the table of contents and skip to the section you need at the moment. Some topics might not apply to your child's Crohn's or you might feel overwhelmed by some information. Try to absorb the information to educate yourself, but be aware of the fact that each child's illness journey is different. I have always found awareness to be a valuable asset. Keep in mind that there will be recommendations, but these are just to guide you, as everyone's journey with Crohn's disease can be different. The same goes for if you are online, researching, or in a support group or on social media; not everyone has the same symptoms or experiences with Crohn's disease.

It's normal for both you and your child to experience complex feelings. For you as a caregiver, it's normal to have some feelings of sadness, doubt, and even guilt, but, realize we make the best decisions as caregivers with the information we have. Try to remember that our kids didn't come with an instruction manual when they were born. We relied on our instincts with parenting along the way. This, too, will happen with your child's Crohn's journey. You also will have feelings of pride in your child's fight. You will see traits of courage, strength, and resilience which might be present from the start or learned along the way.

This guidebook has been written and guided by IBD specialists – gastroenterologists, psychologists, therapists, and patient advocates – who have collectively created this reference to help you navigate different points of this journey, so you can help your child as well as helping yourself. Emotional support is such a key piece to this puzzle of care. School support and knowing your child's rights under the ADA is another key piece. We and our children need to know that we are not alone. Parents need other parents just as kids need other kids who can support and understand this journey. There is a growing IBD community to help. Welcome to our community.

By Ellen Falkenheim
Crohn's disease caregiver and caregiver supporter



Ellen Falkenheim with her daughter

Emotional support is such a key piece to this puzzle of care. We and our children need to know that we are not alone.

¹Inflammatory Bowel Disease is an umbrella term that describes chronic inflammation of the digestive tract.

²GI health refers to gastrointestinal health. There are a range of healthcare providers that focus on gastrointestinal health, including physicians, dieticians, and psychologists.



INTRODUCTION

Inflammatory bowel disease (IBD) is an umbrella term that describes chronic inflammation of the digestive tract. Crohn's disease and ulcerative colitis are two forms of IBD that, together, affect more than three million Americans, including 80,000 children.³ These conditions are painful, medically incurable diseases that attack the digestive system, but can be effectively treated with medications which allows patients to succeed in life. Crohn's disease may attack anywhere along the digestive tract, while ulcerative colitis inflames only the large intestine (colon). Symptoms may include abdominal pain, persistent diarrhea, rectal bleeding, fever, and weight loss. Many patients require numerous hospitalizations and surgery. Most people are diagnosed with IBD between the ages of 15 and 35, however, the incidence is increasing in children.

In 2019, the National Alliance for Caregiving, along with the Crohn's and Colitis Foundation and ImproveCareNow, published *Riding the Roller Coaster of Inflammatory Bowel Disease: A National Study of Caregivers of Individuals with Crohn's Disease or Ulcerative Colitis* to describe the journeys, challenges, joys, and contributions of IBD caregivers—which reported survey feedback from 728 individuals who reported providing unpaid care for someone with IBD. The study found that IBD has a profound impact on the lives of caregivers and highlighted the unmet needs of IBD caregivers. Findings from that study inspired the development of this *Circle of Care Guidebook for Caregivers of Children and Adolescents Managing Crohn's Disease*. This guidebook, developed with the generous support of The Helmsley Charitable Trust, is meant to serve patients, caregivers, and families in their journeys with Crohn's disease by offering effective resources that have helped other caregivers in similar situations.

Crohn's disease, the focus of this *Circle of Care Guidebook*, presents as chronic inflammation that generally affects the ileum—the end of the small intestine—and the beginning of the colon. The disease may also develop in any part of the intestinal tract, anywhere from mouth to anus. Though Crohn's and ulcerative colitis share similar symptoms, Crohn's disease, unlike ulcerative colitis—which affects only the colon or large intestine—can affect any part of the gastrointestinal (GI) tract. Crohn's patients can also experience extra-intestinal manifestations and comorbidities outside of the GI track, with complications in the joints, eyes, skin, bones, kidneys, and liver.

This *Circle of Care Guidebook* will focus on Crohn's disease in children and adolescents. Though the focus of this guidebook is Crohn's disease, some content, specifically information related to patient and caregiver mental health and disease empowerment, is relevant to both caregivers of children and adolescents with Crohn's disease, as well as with ulcerative colitis. This guidebook defines children and adolescents as individuals 18 years of age and younger. Though some information in this guidebook may be relevant to caregivers of adolescents transiting into young adulthood, readers should keep in mind that the information needs of the patient and caregiver will change as the patient transitions and enters into adulthood.

In this guidebook, caregivers are considered parents, guardians, siblings, grandparents, other family members, friends, or another individual who provide(s) unpaid care to a child or children below the age of 18 who are living with Crohn's disease.

The impact and subsequent needs of a family affected by Crohn's disease can vary substantially. The topics selected in this guidebook were informed by caregivers—through a series of listening sessions—as well as by an Advisory Committee consisting of doctors and clinicians focused on IBD patients, mental health experts, and patient advocates. The virtual listening sessions⁴ consisted of 11 parents of children living with Crohn's disease and ulcerative colitis who were diagnosed from ages as young as two to 16. The caregivers were divided into three listening session groups lasting two hours each: one group focused on the experiences of caregivers of younger children with IBD, another group focused on caregivers of adolescents living with IBD, and the third group was focused on the experiences of caregivers of both children and adolescents with IBD. The group was asked open-ended questions related to their daily activities living with a child with IBD, how they managed their child's disease, ways that they engaged their child in disease management, and the challenges they faced as caregivers.

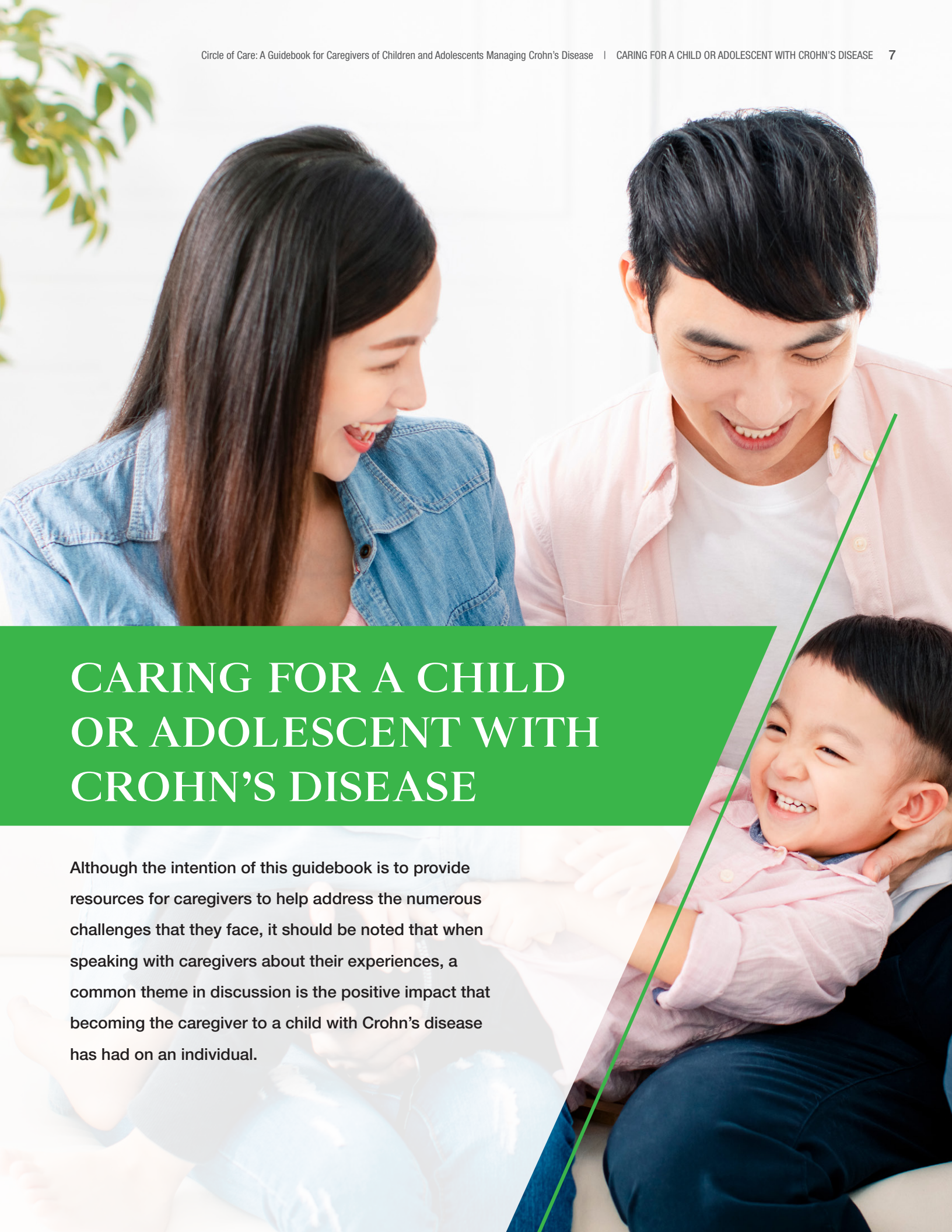
The information presented in this guidebook is based on research. The National Alliance for Caregiving recognizes that the topics in this guidebook are many, in line with the numerous challenges that caregivers face in their journeys. Given the myriad of obstacles and challenges faced by caregivers of individuals with Crohn's disease, the primary intention of this guidebook is to provide a comprehensive set of resources and guidance to address most of the challenges that caregivers face.

You can select topics of interest from the table of contents based on your current experiences or interests. Each section provides information, tools, and resources recommended by other caregivers, as well as professionals that provide support to caregivers and patients living with Crohn's disease. You may also use the [Glossary](#) and [Resources](#) section at the end of this guidebook for key definitions and helpful resources.

The primary intention of this guidebook is to provide a comprehensive set of resources and guidance to address most of the challenges that caregivers face.

³Children's Hospital of Philadelphia. Retrieved from <https://www.chop.edu/conditions-diseases/inflammatory-bowel-disease>, Nov. 20, 2019

⁴Participants of the virtual listening sessions were from diverse cultural backgrounds, however, limitations of these sessions included (1) not having representation of caregivers living in a country besides the United States; and (2) only hearing from the experiences of parents and not caregivers of another relationship to a child with IBD.



CARING FOR A CHILD OR ADOLESCENT WITH CROHN'S DISEASE

Although the intention of this guidebook is to provide resources for caregivers to help address the numerous challenges that they face, it should be noted that when speaking with caregivers about their experiences, a common theme in discussion is the positive impact that becoming the caregiver to a child with Crohn's disease has had on an individual.



POSITIVE IMPACTS

In both listening sessions with caregivers and the *Riding the Roller Coaster of Inflammatory Bowel Disease* study,⁵ many caregivers described positive impacts through their experiences:

Our national study, as described above, found that more than 50 percent of IBD caregivers **take pride** in learning about the care recipient's condition and feel they are a valued part of the healthcare team.

In the listening sessions, caregivers shared that they **felt positive** being connected to the Crohn's disease community with the opportunity to hear and learn from other caregivers through support groups.

Caregivers described **feeling proud** and relieved when observing their child or adolescent managing their disease on their own and feeling empowered to do so.

Some caregivers shared their **gratitude** for having gastrointestinal (GI) doctors that validated their concerns and pushed everything in the right direction quickly for the patient. Caregivers also **appreciated** having interdisciplinary care teams with social workers, therapists, dietitians, doctors, etc. working together for their child or adolescent.

Caregivers shared that they **felt empowered** in advocating for quality care on behalf of their child, as well as advocating for systemic change on behalf of the disease community.

50 percent of IBD caregivers take pride in learning about the care recipient's condition.



CHALLENGES

That said, the challenges faced by caregivers of Crohn's disease are considerable. Below are some examples:

Of the caregivers who reported conducting medical/nursing tasks in our national study, **only about one-third of them received any prior preparation or training** to perform medical tasks.

Despite heavy reliance on healthcare professionals and IBD-specific organizations for information, more than a third of caregivers (35 percent) **felt guilty, believing they should be doing a better job of providing care**. Many caregivers in the listening sessions described experiencing feelings of guilt over whether they gave their child Crohn's disease, that they may have made mistakes in making treatment decisions, or that they didn't do enough to balance the needs of other family members and children.

In our study, nearly a quarter (24 percent) of caregivers reported that **treatment was not available** to their care recipient and more than a third (35 percent) said that they could not handle the management of the condition.

Emotional stress was common among caregivers, with 59 percent finding caregiving to be emotionally stressful, 49 percent feeling overwhelmed, and 44 percent reporting that caregiving affected their mental health. A full 16 percent experienced depression from providing care. Some caregivers in the listening sessions described feelings of PTSD (post-traumatic stress disorder) and worry over when their child's next flare-up⁶ would occur.

More than six in 10 caregivers reported **struggling with a sense of loss** over what the care recipient's life would have been like without IBD. Caregivers in the listening sessions also described worry about mental health, social issues, and financial issues facing their child in the long-term.

Challenges reported by caregivers in the study and in listening sessions included **communicating with doctors**, getting people to understand the seriousness of the condition, dealing with insurance companies, the strain on personal and family relationships, caring for oneself, lack of support, sadness at seeing a child suffer, and getting access to medications.

Recommendations for the field made by survey and listening session participants included **more resources and assistance for caregivers** overall; resources on how to support, advocate for, and empower IBD care recipients; more support groups; more information on alternative/non-traditional treatments; more information about nutrition and diet; and better communication with doctors and other providers. Additionally, caregivers expressed a desire for more support and resources to navigate the health insurance system.

⁵This study was not representative. This study utilized convenience sampling to field the questionnaire and a "non-probability sampling" method to recruit study participants, which allowed participants greater freedom to self-select into the study. In contrast to probability sampling, which purposely selects individuals to be in the study in an effort to ensure representativeness and reduce the potential for bias, in non-probability sampling, the individuals who self-selected into the study may not be representative of all IBD caregiving experiences.

⁶"Flare-ups" are discussed in the Healthcare section.



EVERYDAY EXPERIENCES AMONG CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH CROHN'S DISEASE

Our listening sessions shed light on the day-to-day experiences of IBD caregivers, including:

- Advocating for their care recipient with healthcare providers, schools, or other services/agencies;
- Monitoring the severity of the care recipient's condition;
- Shopping for and preparing meals including specialty foods, which was also reported as being one of the most difficult tasks;
- Attending appointments with health care professionals;
- Talking/communicating with healthcare professionals and insurance companies;
- Providing transportation;
- Providing assistance with medication, doing housework, and managing finances.

Listening session participants contributed tips and recommendations for how to manage these responsibilities.

Diet and Medication Tracking

Most parents reported keeping close track of their child's hydration and what they are eating, as well as staying on track with their child's medication every day. Caregivers reported using pill keepers and dispensers, as well as alarms, to make it easy for their child to learn when and how to take their medication each day. Tracking tools, like these, that caregivers and children can both use, are

helpful in getting children and adolescents ready to take on their own care. Additionally, keeping routines and structure helps the caregiver feel more in control and has the effect of teaching children about how to manage their own disease. For example, reinforcing to a toddler or young child why their medication alarm is going off may help them understand why it's important to take medication: to feel better. Keep in mind that each child is different regarding when they are ready to take on disease management

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and responsibility. Make sure you're communicating with your child about what they are comfortable with taking on, and check in often to see if they want to take more or less on. Stress can be a trigger for Crohn's disease, thus it is important not to add too much to their plate at one time. Even if a doctor recommends that your child take on more responsibility, make sure to have a separate conversation with them to make sure they are ready for that, and feel equipped with the tools needed to do so.

For more tips and tools on how to help your child stay motivated to manage their diet and medication, check out the section on [Empowering Your Child to Manage Their Crohn's Disease](#).

Communicating with Your Child

Nearly every caregiver in the listening sessions reported that the first thing they did every morning was ask their child or adolescent how they were feeling. Communication with your child or adolescent is an important aspect of everyday disease management. Their physical symptoms, as well as mental health status, may impact your child's ability to go to school or go about activities planned for the day. It is also important, however, that caregivers, check in with themselves about any anxiety that they might be experiencing around the child's disease. While asking a child "how are you feeling" first thing in the morning is a normal response to dealing with IBD, a caregiver's unchecked anxiety may also develop into hypervigilance around actually looking for symptoms. When this occurs, a caregiver may unconsciously find themselves filtering out any positive responses that they may be receiving from the child and, instead, focusing on the problem areas.

Nearly every caregiver in the listening sessions reported that the first thing they did every morning was ask their child or adolescent how they were feeling.



Normalizing a child's experience whenever possible can be helpful for both child and caregiver. One way of doing this is by observing the child's behavior and, rather than asking "how are you feeling?", continue on with the normal morning's routine, and allow space for the child to let you know if they are not feeling well. Find ways to bring honesty into your communication with each other so your child can feel comfortable telling you when their symptoms may prevent them from doing an activity or attending school.

For caregivers of young children and toddlers, who can't effectively communicate yet, it can be a day-to-day challenge to distinguish between what is normal childhood growth and development and what is indicative of their Crohn's disease symptoms. For these caregivers, they shared that it was important to leverage their network of other parents to see what's normal for a young child and what isn't.

For children and adolescents, it's important to talk to them honestly about why they are sick, what you can do together and with doctors to make it better, and that the answers won't always be available right away. Young children and toddlers won't question things as much, so it's important to talk to them honestly about the disease to get them prepared for the rest of their lives. As children grow up, they begin to socialize and notice the differences between how they do things and how other "non-IBD" children do things. Older children and adolescents might have more questions, and it's important to answer all questions to the best of your ability, and to have regular, open discussions about the disease. Additionally, it's important for your child to know that they need to speak to you, the caregiver, honestly about how they are feeling. Children may believe they did something wrong to get this illness, or may be scared that the illness is contagious. It is important that the physician and caregivers assess what questions the child may have and give them the correct information.

If, as a caregiver, you are finding it difficult to hear your child's experience or feelings, or simply telling them to "push through it",

it may be helpful to speak to a mental health professional about your own difficulties in dealing with disease management and the difficult emotions that often come with it.

Caregivers also report communicating with their child when it comes to treatment decision-making. From childhood to young adulthood, it's important to balance decision-making for your child and respect their own voice, especially as they get older. Even at a young age, children can be involved in age-appropriate decision-making. One way of doing this is by encouraging your child to speak up at the doctor's office about how they are feeling. This is one way for them to begin to build a collaborative mindset when it comes to their doctors and overall healthcare.

Another way to help your child feel more comfortable voicing their feelings and opinions is to involve them in making a plan together of what to ask and discuss at an upcoming doctor's visit. Children and many adolescents count on their caregivers to be their voice, so it is normal for them to shy away from speaking up. Positive reinforcement is a good way to promote and encourage this behavior. At times, adults feel the need to give children a little nudge in order to get them to speak up, however, children may actually experience shame or embarrassment when this happens and may result in the child shutting down further.

For more tips on communicating with your child about their Crohn's disease and sharing decision-making responsibilities, check out the section on [Empowering Your Child to Manage Their Crohn's Disease](#).

Educating Yourself on the Disease

Many parents and caregivers struggle to find reliable resources about Crohn's disease, as well as resources that are relevant to their child's case. The hospital library is a great resource for evidence-based information. If you are worried about certain medications recommended by your child's doctor, check out the library—online or in-person—for research and quantitative data

on the probability of harmful side effects. Depending on their age and comfort level discussing the topic, share with your child what you've discovered to make informed decisions together. If you have a good relationship with your child's doctor(s), they can also be a great resource to learn more information.

Other educational tools include the Crohn's and Colitis Foundation website and online forums, such as the Crohn's Forum. Keep in mind that before going to your support group or online forum for information, make sure you've gathered enough evidence-based information to differentiate between advice that is beneficial to you and your child and advice or information that isn't. If you have any questions or concerns about something you found or heard about online or in a support group, be sure to ask your child's doctor about it.

Attending Support Meetings

As part of everyday activities, caregivers also report attending support meetings. Therapy and support groups are common forms of resources that caregivers use to stay informed, as well as to manage their mental health needs. Becoming a part of a community can help prevent caregivers from feeling isolated and alone in their experiences and feelings. There are various formats of support groups, both online and in-person. Check out the [Resources](#) section at the back of this guidebook for a list of recommended support groups.

Children and adolescents may also benefit from attending support groups and therapy. It's important that your child knows their mental health is a priority, and if they see you taking care of yourself, they will be more likely to do the same for themselves. Make sure to communicate honestly about mental health resources available to them.

Advocating for Your Child at School

Because your child's Crohn's disease symptoms may sometimes prevent them from attending school every day, or from participating in school-related and extracurricular activities, an everyday part of life for a Crohn's disease caregiver is advocating for their child at school. Crohn's disease is often described as an "invisible" disease, since your child may appear completely healthy on the outside, but suffer on the inside. Therefore, teachers and other students might not understand why your child needs accommodations, so it's important to teach your child to advocate for themselves at school and to educate others on the disease. The more your child's friends and teachers understand the disease, the easier it is to explain why accommodations, like the 504 accommodation plan or an Individualized Educational Plan

Teachers and other students might not understand why your child needs accommodations.



(IEP), are necessary. Make sure to involve your child in educating and telling others about the disease, as well as in advocating for themselves, so that they can do so in the manner and timing that they are comfortable with.

The first step to advocating for your child at school is to educate yourself and your child on the resources and accommodations available. The 504 accommodation plan is commonly used by Crohn's disease patients, and it's important to understand its benefits and to empower your child to use the plan without them feeling like they have an excuse or they are "taking advantage of the system". A 504 accommodation plan allows your child's needs—based on their Crohn's disease—to be met at school. It is important to have a 504 plan in place in case your child needs accommodations during a flare-up or during a complication of disease. You and your child can negotiate the 504 accommodation plan and, once in writing, it will be in effect for an entire school year.⁷ For a list of example accommodations that Crohn's patients often write into their 504 accommodation plan, check out the Crohn's and Colitis Foundation article on "Taking IBD

⁷The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/youth-parent-resources/kids/taking-ibd-to-school>.

to School". For a link to this article and a fact sheet on the 504 accommodation plan, see our [Resources](#) section at the end of the guidebook.

Another accommodation commonly used by Crohn's disease patients is an Individualized Educational Plan (IEP). An IEP is a plan used by children with an intellectual or learning disability and who require specialized teaching. An IEP is available to students in need through the Individuals with Disabilities Education Act (IDEA). A student who has an intellectual or learning disability as well as Crohn's disease, may incorporate their 504 accommodation(s) into the IEP. More information on the difference between an IEP and a 504 accommodation plan is available in the Crohn's and Colitis Foundation fact sheet on the 504 accommodation plan in our [Resources](#) section at the end of the guidebook.

Whatever course of action you and your child decide to take in regards to accommodating their education, you should speak to your child's school's administration and teachers to ensure all parties are on the same page and ready to support your child. It's important to keep regular communication with your child's teachers and school administration to make sure your child is on track in their education and receiving the support they need from the school.

Talk with your child about how much they would like to be involved with informing teachers, guidance counselor(s), and school nurse(s) about their Crohn's disease. If your child is uncomfortable with talking to their teacher, ask if you can do the talking or set up a meeting all together. Come up with a plan together on how your child will communicate to the teacher that they need to use the bathroom, get more water, or take their medication. Some parents described situations where their child's teacher and child had set up discrete, private signals for this ahead of time, such as a discreet hand signal to let the teacher know that they have to go to the bathroom. It's also important for teachers to understand that your child may need to have a water bottle with them in class, or go to the water fountain often, and thus, may need to use the bathroom more often. Caregivers should also make sure teachers are taking what their child is experiencing at face value. For example, if your child is complaining of fatigue and/or an inability to perform a certain activity due to their Crohn's symptoms, teachers should trust them and accommodate accordingly. Having conversations with your child and their teacher ahead of time are important for them to feel comfortable at school.

When possible, parents and caregivers should also connect their child with the school's guidance counselor or social worker. Make sure your child understands that their school's guidance counselor and/or social worker is there to support them if faced with social challenges at school, such as bullying or feelings of isolation.

For more tips on how to advocate for your child at school, connect with other parents or caregivers. The Crohn's and Colitis Foundation chapters and other organization support groups are a great way for you and your child to learn to be vocal in school and healthcare settings. Advocating for your child in a positive way teaches them that they can and should do the same for themselves. Some children and adolescents may not be ready to be vocal with authority figures, so it's important that they observe you so they can one day feel confident to do it themselves.

Advocating for Your Child at the Doctor's Office

Parents are often tasked with advocating for their child at the doctor's office. Like in school settings, parents should involve their children in advocating for themselves in a healthcare setting. At first, you can encourage your child to observe how you talk to insurance companies and healthcare providers. Slowly, you can encourage them to take on some of the communication to learn this important piece of managing their disease and health. Many patients and caregivers have discussions before and after doctor's appointments to prepare for what to expect in the appointment and to discuss possible next steps afterwards. Regardless of what stage of independence your child is at, they should always have you as a resource when advocating for themselves.



Parents should involve their children in advocating for themselves in a healthcare setting.



Stability is important and having your child stay with their IBD specialist during college years is ideal.

Supporting Entrance into the Workforce and College

If your adolescent is ready to enter the workforce, it's important that they understand the accommodations available to help them continue to manage symptoms and be successful at work. Disability protections, such as the Americans with Disabilities Act (ADA), are available to Crohn's disease patients at work. Much like at school, your adolescent should be in control of the manner in which they communicate to their supervisor(s) or co-workers about their Crohn's disease at work. Still, as a caregiver, you can encourage your adolescent to advocate for themselves at work and be informed about the resources available to them. The Americans with Disabilities Act website has information on individuals' rights under the ADA, as well as agencies with ADA responsibilities. See the [Resources](#) section for a link.

Caregivers and/or parents may also play a role in supporting their child with Crohn's disease transition into college. The first step to helping your child through this transition is choosing a college that will provide necessary accommodations to support their success in higher education. Some important things to consider when choosing a college are:⁸

- Proximity to home and/or doctors and hospitals. In case of a flare-up, your child will likely feel more comfortable if they are close to home and/or an IBD hospital or doctor's office. Coordinating care across state lines may be difficult, so you and your child may want to consider utilizing the campus's health services or finding a local gastroenterologist that can partner with your child's primary GI doctor.⁹ Still, stability is important and having your child stay with their IBD specialist

during college years is ideal. Take time with your child to familiarize yourself with all the options to make an informed decision and to help your child feel confident when they are moving away from home.

- Available meal plans. Make sure to ask questions about special options available that meet your child's dietary needs, and/or if it's possible to have a kitchen to cook their own meals.
- Housing accommodations. Your child may need access to a private bathroom or bedroom. If that's the case, you should ask whether your child can sign up ahead of other students.
- Disability services. Many schools have a disability resource center and offer certain accommodations. It's an important step to ensure that the school you pick has a system in place to support students with disabilities. Some accommodations include enrolling for courses early to ensure that your schedule meets the needs of your body, adjusted deadlines and attendance, and note-taking support.¹⁰ It's important to note that your child will still be eligible for a 504 accommodation plan at state universities. The majority of private universities will also offer accommodations if needed, but it's important to look into what accommodations are offered before making a decision.

Your child will likely want to take advantage of the many opportunities that higher education offers, such as study-abroad experiences and scholarship opportunities. Your child may feel that they can't study abroad because of disease limitations. However, you and your child can work with their GI and other

⁸The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/choosing-your-college>. ⁹The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/campus-connection/beyond-college/managing-care-costs>. ¹⁰The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/disability-support>.

specialists to make studying abroad possible. Your child's GI may be able to provide tips on managing medication, accessing reliable healthcare, and managing nutrition while abroad.¹¹ Additionally, there may be vaccines that your child needs to take before traveling abroad. You and your child will want to talk to their doctor about travel plans ahead of time.

There are also scholarship opportunities specifically for students managing IBD and chronic illness. Check out the [Resources](#) section to learn more about scholarship opportunities.

Navigating the Insurance System

Caregivers report spending a lot of time navigating the health insurance system and often find themselves in frustrating situations, lacking the support they need. For more information and resources on the financial aspects of Crohn's disease, visit the [Healthcare: Cost of Care and Access](#) section of this guidebook.

Conclusion

Because managing Crohn's disease is an everyday experience for caregivers of children and adolescents with Crohn's, it has an effect on the caregiver's personal life and the disease may become a part of the caregiver's identity. Many caregivers describe Crohn's disease as becoming a "dominant theme" in the caregiver's and family's life. Managing IBD is, indeed, a family affair that requires understanding and flexibility from all parties involved in the different stages of disease management. Going to doctor's appointments, infusion centers, and attending to the other needs of the patient takes time and energy out of the day for other activities. That being said, for many caregivers, especially those whose child was diagnosed at a young age, Crohn's disease is just a part of what the caregiver associates with raising a child. The same can be said of children and adolescents with Crohn's disease: the disease is just a normal part of their life that they have to manage, and learning to deal with Crohn's is just another part of learning to be an adult.



Managing IBD is, indeed, a family affair that requires understanding and flexibility from all parties involved in the different stages of disease management.

¹¹The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/studying-abroad>.



HEALTHCARE

The following sections of this guidebook were written by Tina Aswani Omprakash.

- Getting Acquainted with Crohn's Disease
- Understanding Symptoms, Flare-ups & Remission
- Understanding & Advocating for Various Medications, Therapies & Surgery for Your Child
- When Something Doesn't Go as Planned
- Health Maintenance, Supplementation, & Vaccination

Tina Aswani-Omprakash is a Crohn's patient and award-winning patient expert and health advocate based out of New York City. She has had Crohn's disease for 15 years and lives with a permanent ileostomy, having had over 20 surgeries to control her disease. Tina maintains a blog and advocacy platform called *Own Your Crohn's* (<http://ownyourcrohns.com>). Her overarching aim is to normalize the rhetoric around chronic illnesses and disabilities in order to help diverse groups of patients own their ailments to live fuller, happier lives.

Tina is currently pursuing her Master's degree in Public Health at Mount Sinai's Icahn School of Medicine. Via her writing, lobbying, social media advocacy, and speaking engagements,

she spearheads public health causes, including those proposing research for and creating awareness for inflammatory bowel disease (Crohn's and ulcerative colitis), life-saving ostomy surgery, gastroparesis, fistulizing disease, and initiatives supporting health equity for women and racial, ethnic, and sexual minorities.

The Crohn's and Colitis Foundation recognized Tina in 2021 for her phenomenal leadership and powerful impact on the IBD community with the *Above & Beyond Volunteer Award*. Tina's blog was also recognized as a 2020 Best Blog by *Healthline* and she was awarded the 2019 *Healio Gastroenterology Disruptive Innovator Award* by the American College of Gastroenterology for moving the needle on GI care for patients.

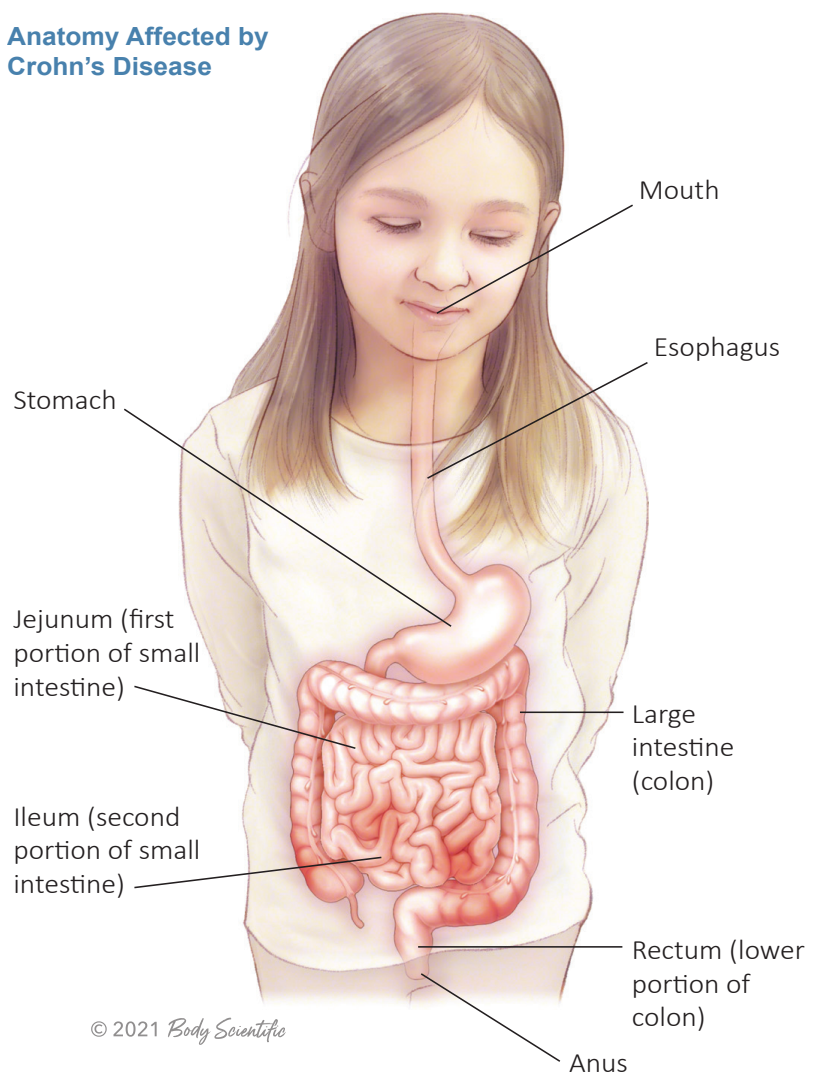


GETTING ACQUAINTED WITH CROHN'S DISEASE

Crohn's Disease is a subset of inflammatory bowel disease (IBD), which is a chronic inflammatory autoimmune condition of the gastrointestinal tract with increasing incidence worldwide. The disease can occur at any age, but Crohn's disease is often diagnosed in children, adolescents, and young adults. According to the National Organization for Rare Disease (NORD), 25 percent of Crohn's patients are diagnosed as children and adolescents, and pediatric Crohn's patients are less likely to experience Crohn's disease that is limited to the small intestine compared to adult patients.¹²

Crohn's disease presents as chronic inflammation that generally affects the ileum—the end of the small intestine—and the first portion of the colon. The disease may also develop in any part of the intestinal tract, including the mouth, esophagus, stomach, rectum, and anus.

Anatomy Affected by Crohn's Disease



¹²The National Organization for Rare Diseases. Retrieved from <https://rarediseases.org/rare-diseases/pediatric-crohn-disease/#:~:text=Symptoms%20may%20come%20and%20go,limited%20to%20the%20small%20intestine.>

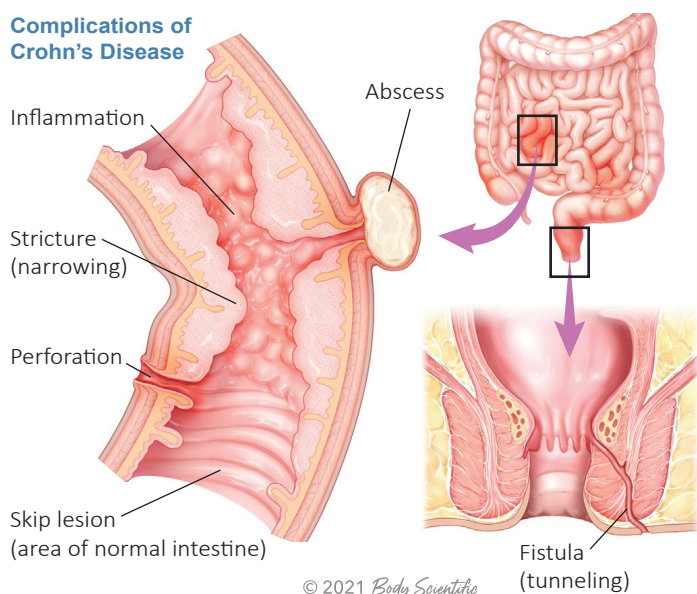
Some additional features of Crohn's Disease include:

- Inflammation within the intestines that may create “skip lesions” exhibited by areas which are inflamed and areas which are normal.
- Stricturing or penetrating disease will involve inflammation of the full thickness of the bowel wall, resulting in bowel obstructions, perforations, strictures, and fistulas throughout the small and large intestines, as well as the rectum and anus. See section below for further explanation.

The following list outlines some complications of Crohn's disease:

- Abscess: A collection of pus caused by bacterial infection. In Crohn's patients, an abscess may form in the intestinal wall or in the perianal region—sometimes causing it to bulge out.
- Bowel perforation: Severe inflammation may result in a hole developing anywhere along the gastrointestinal tract, possibly leading to sepsis; it usually requires immediate surgical attention.
- Fistulizing disease: According to studies, 35-50 percent of Crohn's patients develop at least one fistula. Fistulae are complications of Crohn's that cause damage to the lining of the intestines and result in abscesses and abnormal tunnels between the intestine and another organ (e.g., bladder), or out onto the skin. Many fistulae can develop to the anal region and genitourinary areas (scrotum, penis, vulva, vagina, etc.), and are often referred to as perianal disease. While treatable with medication and/or surgery, fistulae are complications that require immediate medical attention as they can result in passage of feces through unintended parts of the body, causing infections and sometimes sepsis, a serious condition that occurs when the body's response to an infection damages its own tissues.

Complications of Crohn's Disease



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- Stricturing disease: Another complication of Crohn's is an intestinal stricture, which is a narrowing of the intestine from inflammation. It prevents gastrointestinal contents from passing through and can result in intestinal blockages and sometimes bowel perforations.

The Diagnostic Process

Getting a diagnosis for Crohn's disease in a child or adolescent can often be difficult, as many general pediatric practitioners don't often consider IBD. When a child or adolescent presents with abdominal cramping, bloating, distention and/or other symptoms of IBD to a provider, symptoms are usually written off as irritable bowel syndrome (IBS). Misdiagnoses like this leaves the patient's caregiver no choice but to advocate for referrals and/or further testing, especially in the context of bloody diarrhea, weight loss, anemia, and/or an urgent need to move the bowels. Other possible symptoms include eye inflammation, mouth sores, rashes, and joint pain.

Finding the Right Providers

If symptoms persist, pediatricians should refer patients to a pediatric gastroenterologist. Because it can be challenging to locate a pediatric gastroenterologist who specializes in IBD, it is often advised for caregivers to search for the nearest children's hospital or university hospital(s) with an IBD center and a pediatric gastroenterology department. Hospital websites usually allow for searches to be conducted to locate the appropriate physician for your child's care.

Other methods that have proven useful in finding the appropriate pediatric gastroenterologist include the following: (1) contacting the IBD Help Center within the Crohn's and Colitis Foundation¹³ for referrals and information on your local chapter; (2) using the Crohn's and Colitis Foundation website to search for providers; (3) reaching out to patient advocates and advocacy groups for recommended providers in the pediatric IBD community. Caregivers may find other patient advocates through social media, the Crohn's and Colitis Foundation, or other patient advocacy organizations. Please refer to the [Resources](#) section for a list of patient advocacy groups.

Please note that many rural and suburban locations may not have IBD Centers, children's hospitals, or university centers. In such cases, it is advisable to find a pediatric gastroenterologist to manage your child's care locally and to consider a more advanced hospital system with a robust IBD program for second opinions around medication escalation and/or surgery.

¹³The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/community-support/ibd-help-center>.

If surgery is recommended at any point in the patient's journey, it's also important to locate a colorectal surgeon who specializes in IBD. Again, such a surgeon can be a challenge to find outside of major city centers in rural areas and suburbs. One recommended course of action is to work with an IBD specialist at a children's hospital or advanced IBD center. The specialist can refer the patient to a colorectal surgeon within the same hospital system to manage the patient's care appropriately. When considering a surgery, remember you don't necessarily have to go to the surgeon in that same system. It is advisable to get a few opinions and see who is the best match for your child and their needs (see section on [Seeking a Second Opinion](#)).

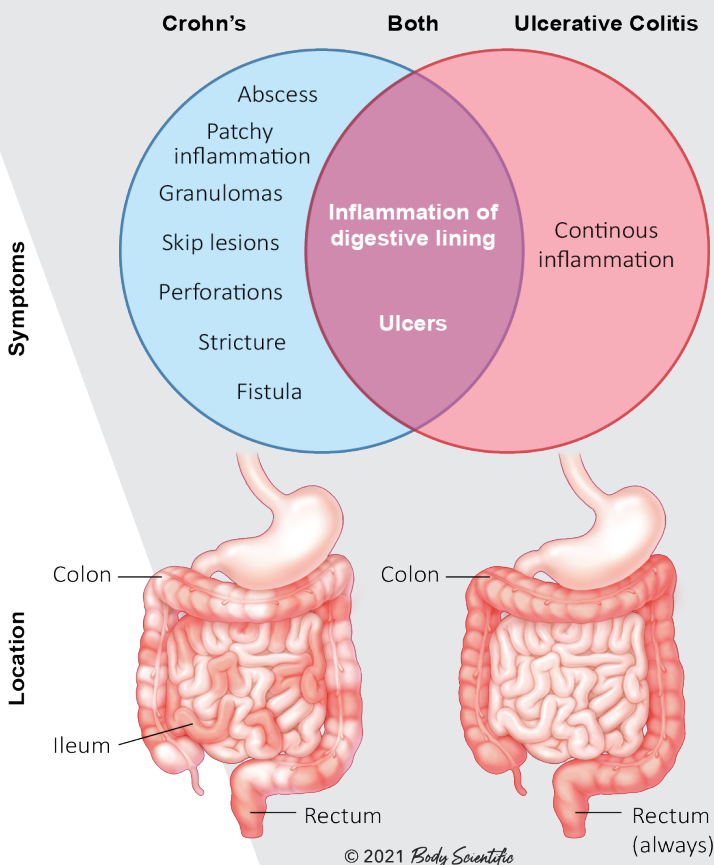
Making the Diagnosis

Once the patient and caregiver meet with the appropriate pediatric gastroenterologist, they can proceed with testing to make a diagnosis. The gastroenterologist will usually start with a consultation, asking for symptoms and all records from the pediatrician or previous gastroenterologist (GI). The GI doctor will usually check inflammatory markers in blood (c-reactive protein, sedimentation rate, etc.) and stool (fecal calprotectin). In addition,

the GI doctor may also rule out any infection that could be causing similar symptoms (e.g., GI pathogens, such as norovirus, *C. difficile*, shigella, salmonella, *E. coli*, etc.).

Usually, if blood work and/or stool studies indicate elevated levels of inflammation, the gastroenterologist will order an upper endoscopy and colonoscopy with biopsies to check if IBD may be causing the symptoms in the colon, rectum, and/or terminal ileum. These scopes are only able to evaluate a small section of the small intestine (duodenum and terminal ileum), and further imaging is needed to assess the rest of the small intestine such as magnetic resonance imaging (MRI) or a computerized tomography (CT) scan. Imaging of the small intestine allows the doctor to assess the degree and location of inflammation and whether a patient has a stricture and/or a fistula in order to recommend the appropriate treatment.

If inflammatory markers are within normal levels, this may be an indication of irritable bowel syndrome (IBS) or other digestive ailments. If this is the case with your child or adolescent, consult your child's gastroenterologist, especially if your child's digestive symptoms persist.



Distinguishing Between Crohn's & Ulcerative Colitis

Distinguishing between Crohn's disease and ulcerative colitis is complex and can cause confusion in providers. If they are unable to distinguish between Crohn's disease and ulcerative colitis in a patient, providers may diagnose the patient with indeterminate colitis, especially if the inflammation and ulcerations are only present in the colon and rectum and without the typical penetrating features and skip lesions that Crohn's patients may have. If Crohn's is present in the colon, the patient may be diagnosed with Crohn's colitis, which does NOT refer to having both ulcerative colitis and Crohn's disease. As such, in recent years, Crohn's disease and ulcerative colitis—and the specific locations the disease presents in—are being referred to as a spectrum or continuum of inflammatory bowel diseases, rather than two separate diseases. Many doctors now focus more on the location of the disease and how it is presenting rather than categorizing the condition as specifically Crohn's or ulcerative colitis.

Integrating Care

Another important feature of an advanced IBD center within a children's hospital or university center is that care may be integrated with a clinical psychologist or social worker and registered dietitian that specialize in IBD. This allows gastroenterologists and colorectal surgeons to work together to liaise with the gastro-psychologist or social worker and GI dietitian presiding over your child's care. Care integration ensures that care is centralized and optimized from a medication, surgical (if needed), psychological, social, and nutritional standpoint.

Advanced IBD centers try to integrate these practices into their care to allow the pediatric patient automatic access to other practitioners in the center in addition to their gastroenterologist. However, if you are not able to visit an advanced IBD center, there are ways to find a clinical gastro-psychologist or social worker and registered dietitian separately to help manage your child's care.

One way to find a clinical gastro-psychologist or social worker and registered dietitian is to ask the child or adolescent's gastroenterologist or colorectal surgeon for a referral to psychology and nutritional services. Other ways are listed below.

How to Find a Registered Dietitian

Registered dietitians are often an integral part of a pediatric IBD patient's care. As discussed in the [Nutrition & Dietary Therapies](#) section to follow, dietitians work with the pediatric gastroenterologist to recommend modifications to diet, as well as nutritional supportive therapies to patients and their families. Often, if a dietician is not embedded within the GI team you see, the GI will have outpatient referral recommendations, as this is common. To find a dietitian who specializes in digestive diseases, you can visit the International Foundation for Gastrointestinal Disorders (IFFGD) website¹⁴ for a listing of U.S. and international dietitians. Another website to search for a dietitian is the Academy of Nutrition & Dietetics.¹⁵

How to Find a Mental Health Provider

Late childhood and adolescence are times of emotional, cognitive, and social transition, and oftentimes coincide with the peak age of onset of pediatric IBD. As such, an IBD diagnosis can have an immense psychosocial impact on pediatric patients.¹⁶

As adolescents approach puberty and explore their own identity, managing an illness such as IBD can become even more challenging. Patients may feel embarrassed due to fecal



As adolescents approach puberty and explore their own identity, managing an illness such as IBD can become even more challenging.

incontinence and poor body image due to disease or medication-related weight loss or gain. They may feel social anxiety due to a lack of familial understanding, absences from school, and a loss of friendships and social activities. These ongoing stressors at home and in school may influence how children will react to having IBD.

It is therefore important to consider engaging a mental health provider who is well-versed in chronic illness (and IBD, if possible) in your child's care. As stated earlier, some advanced IBD centers have GI psychologists and/or social workers who can work with your child in terms of gut-directed psychotherapy. In other cases, it is vital to find a mental health specialist privately to help your child navigate and accept an IBD diagnosis. It is not necessary to wait until you feel your child "needs" mental health support, rather it is ideal to establish a relationship with a provider your child clicks with and have them as a resource for whenever your child wants support.

Finding a mental health specialist who understands the nuances of IBD can be challenging. The recommended method is to search the newly formed Rome Foundation Psycho-gastroenterology directory.¹⁷ The Rome Foundation is an international consortium of physicians and psychologists specializing in digestive disease diagnosis and treatment.

¹⁴The International Foundation for Gastrointestinal Disorders (IFFGD). Retrieved from iffgd.org. ¹⁵The Academy of Nutrition and Dietetics. Retrieved from eatright.org. ¹⁶Psychosocial Issues in Pediatric Inflammatory Bowel Disease: A Clinical Report of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3609923/>, 2014. ¹⁷The Rome Foundation Psychogastroenterology directory. Retrieved from <https://romegastro.org>.

Another website to consider is the *Psychology Today Therapist Finder*¹⁸ website to look for a mental health provider who works with patients with chronic medical illnesses. There are several options to filter your search on this site. You will want to check off the following items:

Issues:

- Chronic Illness

If using google, search “IBD Therapist + your city” (e.g. “IBD therapist NYC”)

Types of therapy to consider:

- Cognitive Behavioral Therapy (CBT)
- Acceptance and Commitment Therapy
- Mindfulness Based (MBCT)
- Solution Focused Brief (SFBT)

To further narrow down the search, you can search for the below specialties:

- Behavioral Medicine
- Health psychology
- Specific chronic medical conditions like lupus, cancer, rheumatoid arthritis, diabetes
- Chronic medical illness

Many therapists offer a free phone consultation for prospective patients and should take the time to answer any questions you have to ensure they are a good fit for your child. Below are some important questions to ask:

- When is your soonest opening?
- Do you offer virtual or in-person sessions?
- What is your approach to treatment? You can ask specifically for the age range of the child.
- How many people have you seen with IBD?
- Do you have any specialty training in working with those with chronic medical illness?
- As a parent/caregiver, how will I be able (or expected) to support my child's treatment?
- How long does your typical patient work with you?
- Do you accept my insurance?
- How will you work with my child's medical team/physician?
- What are your fees?
- Do you offer sliding scale if you do not accept my insurance?



UNDERSTANDING SYMPTOMS, FLARE-UPS & REMISSION

Symptoms of inflammatory bowel disease may vary from person to person, depending on the severity and the location of each patient's inflammation. Symptoms may range anywhere from mild to severe and patients often experience periods of active disease followed by periods of remission.

Some common symptoms of IBD may include:

- Diarrhea;
- Blood & mucus in stool;
- Abdominal pain and cramping;
- Urgency to use the bathroom;
- Decrease in appetite;
- Unexplained fatigue;
- Unintended weight loss;
- Fevers;
- Nausea and/or vomiting; and
- Anemia.

Many of these symptoms, including abdominal pain and cramping, blood and mucus in stool, along with urgency and fevers, can arise from inflammation and ulceration of the intestines. Diarrhea can result from the inability to absorb nutrients and water due to inflammation. As a result of blood loss and diarrhea, patients may experience anemia, unintended weight loss, in addition to severe fatigue. Additionally, anemia may result from low iron levels and poor absorption of vitamins and minerals. When inflammation is severe, patients may be unable to keep food down and develop nausea and vomiting which can result in a decreased appetite. Fevers may spike, especially in the presence of abscesses and fistulae. For more information, see the section on [Understanding & Advocating for Various Therapies & Medications for Your Child](#).

¹⁸Psychology Today Therapist Finder. Retrieved from <https://psychologytoday.com/us/therapists>.

Extraintestinal Manifestations and Comorbidities in IBD

As described above, inflammatory bowel disease can cause a variety of symptoms, both inside and outside the intestines. When the disease affects a part of the body outside the intestines, this is known as an extraintestinal manifestation (EIM) of IBD.

According to the Crohn's and Colitis Foundation, approximately 25-40% of IBD patients experience EIMs.¹⁹ The most widely diagnosed EIMs include inflammation of the joints, skin, eyes, bones, liver, and kidney:

- **Joints:** One of the most common EIMs is arthritis. Many IBD patients can develop joint aches and pains, others can have inflammation of the small and large peripheral joints (fingers, toes, ankles, wrists, etc.), while others can develop more severe forms of inflammatory spondyloarthritis. Another common diagnosis is sacroiliitis, which is chronic lower back pain. Others may live with another disease other than IBD (comorbidities), including rheumatoid arthritis and ankylosing spondylitis (fusion of the small bones of the spine).
 - These symptoms and diagnoses may precede an IBD diagnosis or develop after diagnosis.
 - In some cases, these symptoms may be indicative of worsening IBD. It is best to address joint symptoms to your child's gastroenterologist for a referral to coordinate your child's care with a pediatric rheumatologist.
 - It's important to consider a bone density scan at regular intervals every few years, or as recommended by your child's care team in order to keep tabs on your child's bones, especially in light of steroid use. You can find more information on this in the [Healthcare Maintenance](#) section.
- **Skin:** Dermatological manifestations can also develop in IBD patients. From erythema nodosum to pyoderma gangrenosum and hidradenitis suppurativa, in addition to Sweet's syndrome, many different forms of skin lesions can develop in IBD patients, particularly in cases of worsening IBD. Psoriasis, eczema, and atopic dermatitis can also be comorbidities of IBD.
 - Many of these diagnoses may precede an IBD diagnosis and may be an indication of gut-related issues or of worsening disease after an IBD diagnosis has been made.
 - It's important to show any and all skin lesions to your child's gastroenterologist so they can make an appropriate diagnosis and/or refer you to a

dermatologist for a biopsy and treatment of the skin manifestation. It may also be recommended to receive yearly skin exams.

Many joint and skin manifestations come secondary to IBD and are often treated concurrently with biologics and/or immunosuppression. See more on the section about [Understanding & Advocating for Various Therapies & Medications for Your Child](#). In some cases, once IBD inflammation settles down, a patient's joint and skin symptoms may also remit to some extent. Coordinating care here is of utmost importance, as patients may sometimes need topical steroids and/or other therapies from specialists to treat these conditions more locally. It is always best to discuss these manifestations with your child's gastroenterologist to understand how to treat the EIM.

There are other extraintestinal manifestations to consider, as well, when caring for your child or adolescent's IBD:

- **Eyes:** Eye issues can present as eye irritation, redness, and/or itching. Some common eye problems that exist in IBD patients include the following:
 - **Uveitis:** inflammation of the uvea, which consists of the layer and structures of the eye beneath the white of the eye (sclera);²⁰
 - **Scleritis:** inflammation of the white of the eye;²¹
 - **Episcleritis:** inflammation of the outer coating of the white of the eye;²²
 - **Keratopathy:** abnormality of the cornea;²³
 - **Dry eyes:** a secondary problem that can be associated with any of the above conditions, vitamin A deficiency, and/or eye allergies.

For some IBD patients, eye problems may be the first sign that they are developing IBD. For others, eye issues are complications that can occur on and off while living with IBD. It's important to raise any eye-related concerns with your child's gastroenterologist and work with an ophthalmologist to manage any chronic eye manifestations of IBD, as well as have annual check-ups.

- **Liver:** In some IBD patients, the liver can become inflamed or damaged. Some liver manifestations of IBD include:
 - **Primary Sclerosing Cholangitis (PSC):** PSC often does coexist with IBD. PSC is inflammation in the bile ducts which causes scarring and could lead to cirrhosis down the line.
 - **Hepatitis:** this can also coexist as another autoimmune disorder with IBD. It leads to inflammation of the liver.

¹⁹The Crohn's and Colitis Foundation. Retrieved from [https://www.crohnscolitisfoundation.org/what-is-ibd/extraintestinal-complications-ibd#:~:text=When%20the%20disease%20affects%20other,that%20IBD%20patients%20may%20experience](https://www.crohnscolitisfoundation.org/what-is-ibd/extraintestinal-complications-ibd#:~:text=When%20the%20disease%20affects%20other,that%20IBD%20patients%20may%20experience.). ²⁰IBD Relief. Retrieved from <https://www.ibdrelief.com/learn/complications-of-ibd/eye-problems-in-ibd/eye-problems-uveitis-crohns-disease-and-ulcerative-colitis>. ²¹IBD Relief. Retrieved from <https://www.ibdrelief.com/learn/complications-of-ibd/eye-problems-in-ibd/scleritis-crohns-disease-and-ulcerative-colitis>. ²²IBD Relief. Retrieved from <https://www.ibdrelief.com/learn/complications-of-ibd/eye-problems-in-ibd/episcleritis-eye-problems-in-crohns-disease-and-ulcerative-colitis>. ²³IBD Relief. Retrieved from <https://www.ibdrelief.com/learn/complications-of-ibd/eye-problems-in-ibd/keratopathy-crohns-disease-and-ulcerative-colitis>.



Remission is often characterized by a decrease or disappearance in IBD symptoms and is the goal for doctors and their patients alike in their treatment plan.

- **Cholecystitis:** This is inflammation of the gall bladder mostly due to gallstones blocking the bile duct. Gallstones can also be an extraintestinal manifestation of IBD.

Liver issues are usually monitored during routine bloodwork. If detected in testing, it is important to discuss any abnormal liver functions with your child's gastroenterologist and consider a referral to a hepatologist (liver specialist) for more specialized monitoring, testing, and treatment.

- **Kidney:** The kidneys filter the body's blood supply and eliminate waste through urine. Some kidney manifestations of IBD include:
 - **Kidney stones**
 - **Hydronephrosis:** an obstruction of one of the ureters (the tubes connecting the kidney to the bladder).
 - **Fistulas:** abnormal tracts between the intestines and adjacent organs, including the bladder or ureter. These can cause urinary tract infections and sepsis, and may require close monitoring and immediate care.
 - **Glomerulonephritis:** inflammation in the kidney that limits its filtering ability (this is rare).
 - **Amyloidosis:** an abnormal deposit of protein into the kidneys (this is rare).

Sometimes IBD medications negatively affect liver and kidney functioning, however, functioning generally improves upon stopping those medications. There is always a risk-benefit calculation when considering medication and treatment options and it's important to speak to your child's doctor regarding regular testing and bloodwork to keep tabs on your child or adolescent's

health status. If your child experiences multiple urinary tract infections or bladder infections, it may be worth getting a urologist or nephrologist involved based on your child's gastroenterologist's recommendations.

What Is Remission?

Remission is often characterized by a decrease or disappearance in IBD symptoms and is the goal for doctors and their patients alike in their treatment plan. Remission, however, has a variety of meanings for IBD patients and their caregivers. For many patients and caregivers, remission might mean diminished symptoms, including reduction in abdominal pain, diarrhea, and/or bloody stools.

However, even if patients are not experiencing symptoms, they may still have inflammation as seen through colonoscopy and/or imaging studies (CT/MRI scans). Thus, symptoms do not provide the full story and looking at symptoms for signs of remission can be misleading. As such, the term remission is best described as a variety of types of remission, including the following:

- **Biochemical remission:** Laboratory blood and/or stool studies indicate that inflammatory biomarkers or other markers consistent with IBD are within the normal range.
- **Clinical remission:** IBD symptoms have lessened to the degree that they are mostly absent or gone.
- **Endoscopic remission:** No inflammation is visualized upon a colonoscopy and biopsy.²⁴
- **Histologic remission:** This type of remission indicates that the patient is endoscopically and clinically in remission; not

²⁴Retrieved from <https://www.verywellhealth.com/endoscopic-remission-ibd-405290>.

only is there a reduction in symptoms, but there is also no indication of inflammation through a colonoscopy and biopsy. Patients with this type of remission have the best long-term outcomes.

- **Surgical remission:** Surgery can bring about remission for a period of time in some IBD patients. For Crohn's patients, this form of remission may be short-lived as the disease can reoccur and may require medical management even after surgery.

To a gastroenterologist, one of the most important aspects in helping patients achieve remission is to minimize steroid use through the help of advanced therapies, also known as achieving steroid-free remission. Steroids and advanced therapies are discussed in greater detail in the following section on [Understanding & Advocating for Various Therapies & Medications for Your Child](#). Though steroids can be very effective, their use can come with heavy side effects that can worsen with more frequent, prolonged use. Achieving histologic remission is also an important goal for a gastroenterologist in treating your child's Crohn's disease, as this kind of remission has the best long-term outcomes.

Regardless, your child's gastroenterologists will be interested in seeing your child growing, gaining weight, feeling well, and making sure that your child doesn't have grossly active disease that can cause Crohn's disease complications.

To a gastroenterologist, one of the most important aspects in helping patients achieve remission is to minimize steroid use through the help of advanced therapies, also known as achieving steroid-free remission.

When to Contact Your Provider

There are many instances that may warrant contacting your child or adolescent's doctor. Always use your judgment when contacting the GI doctor.

Below is a list of possible scenarios when it would be important to reach out to your care team:

- Fevers above 100.4 F (38 C): spiking a fever can be indicative of an infection or increasing inflammation that your child's body may be trying to fight.
- Significant diarrhea and rectal bleeding.
- Dehydration, dizziness, and rapid heartbeat: these may or may not all be linked to dehydration. Signs of dehydration include the following:
 - Muscle Cramping (legs, feet, etc.);
 - Dry skin and mouth;
 - Decreased urine output;
 - Loss of fluid due to diarrhea;
 - Dark-colored urine;
 - Excessive thirst;
 - Blurred vision or lack of balance;
 - Tachycardia (rapid heartbeat).
- Inability to eat, drink, or keep anything down.
- Severe abdominal pain and cramping.
- Severe nausea and vomiting: could indicate an intestinal obstruction.
- New or worsening extraintestinal manifestations: manifestations in the skin, joints, eyes, etc. can all be indicative of potentially worsening IBD.
- Complications including perianal abscesses and fistulas that may present and cause pain.
- Suicidal ideation and/or mental health concerns.

All of the above scenarios warrant contacting and being assessed by your child or adolescent's primary care doctor who will work closely with the gastroenterology care team. If fevers spike, vomiting begins, dehydration becomes too difficult to manage at home, and/or if pain become too severe for your child to bear, it's best to consider a visit to the emergency department for prompt care.

In situations like these, it is important to call the doctor's office during office hours to discuss first. If it is an evening or weekend, call the answering service and ask to speak to the doctor on call. If the doctor on call thinks it's time for an emergency room visit, please take your child or adolescent to the emergency room for immediate care.



UNDERSTANDING & ADVOCATING FOR VARIOUS MEDICATIONS, THERAPIES & SURGERY FOR YOUR CHILD

Medications & Therapies for Crohn's Disease

Intestinal inflammation often makes it difficult for children's bodies to absorb the nutrients needed to help them grow and gain weight. Impaired bone growth and delayed puberty may also become an issue in children living with Crohn's disease.

While there is currently no cure for Crohn's disease, there are a variety of medications, surgeries, and other therapies that may help in the management of pediatric Crohn's disease.

Exclusive Enteral Nutrition (EEN)

Once a Crohn's diagnosis is confirmed, in some IBD Centers around the U.S., exclusive enteral nutrition (EEN) may be the recommended first-line therapy to treat active Crohn's disease. EEN is a nutrition-based formula delivered either orally or via feeding tube.

EEN is designed to provide a flow of liquid formula, which allows for better absorption of nutrients and fewer symptoms associated with Crohn's disease (e.g., less distention, less abdominal cramping, and less vomiting). It may be a short-term program of 8 to 12 weeks or a longer-term plan of care depending on each patient's case and the gastroenterologist's opinion on the best course of action.

It is important to note that EEN may not be an appropriate treatment option for all pediatric Crohn's patients, as it may be difficult for a child or adolescent to sustain a liquid diet. EEN can help to induce remission in some patients while others may need to be escalated to medicinal therapies using enteral nutrition as an adjunct treatment. It is best to always discuss treatment options with your child's physician.

Medical Treatment Options

Your child's gastroenterologist may discuss prescribing medications to control inflammation and ease symptoms, especially if the doctor does not notice significant improvement with EEN or if your child's IBD appears to be moderately to severely active. Medical treatment for Crohn's disease has two

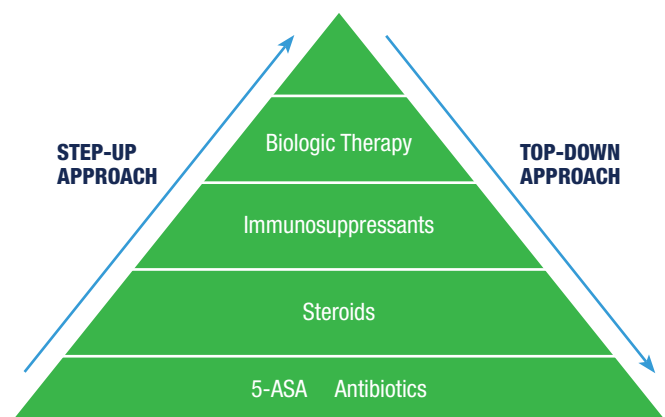
main goals: (1) achieving remission—resolution of inflammation leading to symptom resolution; and (2) maintaining remission long-term. Treatment is aimed at controlling the source of IBD symptoms, which is the ongoing inflammation in the intestines.

See the following page for medications approved to treat IBD.

Step-Up vs. Top-Down Approach

In pediatric Crohn's disease, there are two schools of thought when it comes to treatment: (1) the Step-Up approach, an older algorithm of how to treat a patient; or (2) the Top-Down approach, a model that suggests that proactive therapy upon disease onset may result in fewer complications and surgeries by placing a patient on the most effective medication at the time of diagnosis to induce remission the fastest and prevent complications.

The approach an IBD specialist takes varies based on the patient's individual circumstances and is often a shared decision. In milder cases of pediatric Crohn's, the 5-ASA class of medications is often said not to provide much benefit, if any at all. However, if a Crohn's patient is suffering from colonic involvement, sulfasalazine may be used for treatment, and budesonide may be used for patients with terminal ileitis Crohn's disease. When a patient presents with mild disease, EEN is considered. If the disease worsens rapidly, the doctor decides how to modify therapy, which approach to take, and when it may be necessary to involve a colorectal surgeon to discuss surgical options with the family.



THERE ARE MANY MEDICATIONS APPROVED TO TREAT IBD, SUCH AS:

5-ASAS

Aminosalicylates may be prescribed to control inflammation in the lining of the digestive tract. They are mainly used to treat mild to moderate ulcerative colitis. Due to lack of efficacy, many gastroenterologists have moved away from using 5-ASAs to treat Crohn's disease.

- Aminosalicylates may come in the form of pills, enemas, or suppositories inserted through the rectum. The type taken depends on several factors, including where in your digestive tract the inflammation is located.
- 5-ASA drugs are prescribed for maintenance treatment and are used to prevent flares of the disease. They need to be taken for many years, even when the patient may be feeling better and having few, if any, symptoms or flares.

CORTICOSTEROIDS

Corticosteroids are hormones produced by the adrenal glands. They have many important functions in the body, including control of inflammatory responses.

- Steroid medications are anti-inflammatory and work by suppressing the immune system. Steroids may be helpful in IBD flares and are often used as a bridge to a more longer-term medication therapy in IBD.
- Steroids are not helpful in preventing future flares and should not be taken for long periods of time due to their side effect profile. In some cases, using steroids for longer timeframes might result in complications of Crohn's disease, including abscesses and fistulae.
- Most steroid medications for IBD come in pill or liquid form, but they can also be administered rectally as an enema, suppository, or foam. In acute flares and hospitalizations, steroid infusions are also possible.

SMALL MOLECULES

In IBD, small molecules refer to organic compounds that are directed at specific inflammation-causing pathways.

- Small molecules are generally used to treat moderate –to severe IBD. They mostly come in oral form, unlike biologics, making them more patient-friendly.
- Each small molecule therapy works differently and has a different safety and side effect profile. It is best to discuss which option may be optimal for your child with their gastroenterologist.

IMMUNOMODULATORS

These work to calm the overly active immune response that results in Crohn's-related inflammation. They are most often used in moderate to severe Crohn's disease.

- There are oral immunomodulators, as well as injectable ones. These medications can take approximately 2 to 3 months to start working, so, steroids or exclusive enteral nutrition (EEN) are often used to induce remission and immunomodulators are used to maintain remission.
- This class of medication can be very effective in maintaining steroid-free remission in moderate –to severe cases of IBD. Unlike steroids, these medications can be used safely for a long time. It is important to continue the immunomodulator even when feeling well.
- Immunomodulators were initially developed as treatments for cancer. While they carry some side effects, this class of medication may be needed to treat the patient's brand of IBD. It is best to speak to your child's gastroenterologist recommending this medication to understand the risk-benefit profile.

ANTIBIOTICS

In some cases, the inflammation in IBD may be caused by the proliferation of intestinal bacteria. By killing off and controlling the growth of such bacteria, antibiotics may help to curb IBD flares. In Crohn's disease patients, antibiotics may be used to treat abscesses caused by Crohn's disease complications.

- Antibiotics may also be used to prevent bacterial growth and sepsis caused by complications of Crohn's disease, including abscesses, fistulae, and strictures.
- Antibiotics must be carefully administered as patients can develop other complications including antibiotic resistance and *C. difficile* infection from overuse.

BIOLOGICS

Biologics are antibodies developed in the laboratory that stop certain proteins in the body or in the gut from causing inflammation. Biological therapies offer mechanisms of action that are more precisely targeted to the pathways that may result in Crohn's-related inflammation.

- Biological therapies are often used to treat moderate –to severe cases of Crohn's disease. They can come in the form of injectables and/or intravenous infusions.
- Biologics are generally considered steroid-sparing therapies in that they have a better safety profile than most corticosteroids, and are often used as long-term treatment to prevent disease relapse and induce remission.
- There are many different pathways that biologics currently target and many more in the pipeline waiting to be developed and tested. Some common pathways include anti-TNF (tumor necrosis factor), anti-integrin (gut-focused biologics), and anti-IL-12/IL-23 agents. While gastroenterologists may commonly prescribe biological drugs such as Vedolizumab and Stelara to treat adult Crohn's patients, these brands are not FDA-approved for pediatric patients. This is why a biologic anti-TNF is often the first line therapy for pediatric patients due to the existence of over 20 years of medical evidence.
- Each biological agent works differently and has been studied for different variations of disease activity (e.g., one may have better data for treating fistulizing Crohn's versus another). Each one also has a different side effect profile. It is always best to discuss which option may be the optimal fit given your child's disease presentation and location with the gastroenterologist.
- Biologics are often expensive to develop, may require additional insurance prior authorizations, and are often costly for patients to afford. It is best to consult your doctor's office, insurance specialty pharmacy program, and the pharmaceutical company for patient assistance programs. There is additional information on this topic in the section [Cost of Care and Access](#).

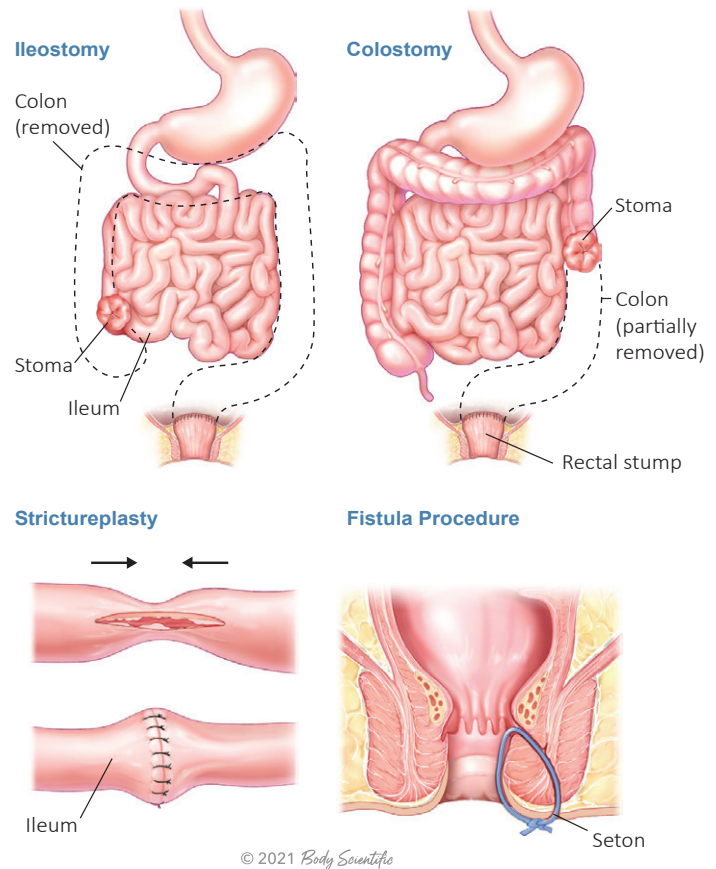
Sometimes combinations of the above-listed therapies are used to bring the disease into remission. The class of medications a gastroenterologist prescribes depends on each individual's severity of the disease. Deciding on a treatment option should be a shared decision amongst the doctor, the patient, and the patient's family.

Surgical Options for IBD

Sometimes medication is not enough to treat the patient's Crohn's disease, and surgery may be required. When medications are unable to sufficiently control the extent of the disease or the patient developed a complication, such as a fibrostenotic stricture or fistula, areas of severely diseased bowel can be removed and reconnected. Sometimes an ostomy (external collection of feces into a pouch) may also become a viable option. See below to learn more about the different surgeries for IBD:

There are many types of surgery for Crohn's disease patients, including:

- **Proctocolectomy:** removal of the diseased colon or rectum.
- **Hemicolectomy:** removal of a portion of the diseased colon.
- **Resection:** removal of a diseased or strictured portion of the small or large intestine.
 - This may be required to surgically correct a bowel perforation or a stricture, or it may be a staged surgery, requiring a temporary ostomy. Sometimes, depending on the location and severity of the disease, a permanent ostomy may be recommended.
- **Ostomy:** External collection of feces into a pouch.
 - There are two types of ostomies given to IBD patients: colostomy—abdominal opening via the colon—and ileostomy—abdominal opening via the small intestine.
 - Colostomies are usually given in hemicolectomies where a portion of the colon is salvageable.
 - Patients are given an ileostomy when the entire colon is severely diseased and a proctocolectomy is required.
 - A temporary ostomy is often given temporarily to allow resected bowel, stricture, or fistula to heal. It is most commonly administered in resections and in proctocolectomy with j-pouch/IPAA to allow the bowel to rest prior to reconnection.
 - A permanent ostomy is given in cases where the temporary ostomy cannot be reversed due to ongoing severe inflammation, including fistulizing or stricturing disease. This surgery is often done in Crohn's disease upon proctocolectomy.
- **Strictureplasty:** repairs a stricture or narrowing of the intestine by widening the narrowed area without removing any portion of the intestine. This widening helps to preserve as much of the bowel as possible and minimizes the risk of developing short bowel syndrome.
 - Strictureplasty may result in a temporary ostomy depending on the location of the stricture. The ostomy may or may not be reversible depending on the patient's individual situation and surgical outcome.



- **Abscess drainage:** when a collection of pus develops from Crohn's or as a surgical complication, it may need to be lanced and drained. Depending on the complexity and size of the abscess, a drain may have to be left in for some time to allow the collected fluid and infection to dissipate.
- **Fistula procedures:** the development of fistulae can require immediate medical attention to prevent infection, worsening disease, and sepsis. Common surgeries for fistulae may include:
 - Placing a surgical band, or seton, into and around the fistula to allow for proper drainage and promotion of healing.
 - Diverting the portion of the intestine that is fistulizing to create a temporary ostomy, allowing stool to bypass the fistula via the ostomy site to promote healing. The temporary stoma created via diversion may or may not be reversible depending on the patient's individual situation.
 - Opening the fistula up with an incision along its length to allow it to drain and heal.
 - Placing a medical plug or glue to seal the fistula so that there is an opportunity for it to heal.

Complications of Surgery

Any surgery can come with complications that may require additional medical or surgical intervention. For example, there may be abscesses or infections after surgery that may need to be treated with antibiotics or require additional surgery to drain.

Though rare thanks to newer medication, another complication to keep in mind is **short bowel syndrome (SBS)**. If too much of the small intestine is resected, Crohn's patients can develop SBS. The small intestine helps to absorb many of the nutrients we consume from eating. SBS makes the body unable to absorb enough nutrients from foods eaten because there is not enough small intestine to aid in the absorption process, leading to diarrhea, weight loss, dehydration, and malnutrition, among other symptoms. It is always best to discuss therapy options with your child's physician to determine which options maximize benefits and minimize risks for each individual pediatric IBD patient.

Setting realistic expectations is important in regards to surgery, especially when it comes to ostomy- and/or fistula-related surgeries. Coordinating with a mental health counselor for yourself as a caregiver and your child or adolescent may be something to consider prior to surgery. See more about this in the above section on [Finding a Mental Health Provider](#).

Setting realistic expectations is important in regards to surgery, especially when it comes to ostomy- and/or fistula-related surgeries.

Nutrition & Dietary Therapies

Good nutrition plays a vital role in managing IBD as the disease can pose nutritional challenges for children. These challenges include:

- **Decrease in appetite due to increased inflammation:** this may lead to the child not being able to eat enough to sustain energy levels and growth.
- **Lack of nutrient absorption:** during times of inflammation, the digestive tract may not absorb nutrients as well as it should, or the body may not use or allocate nutrients appropriately.
- **Need for more calorie intake:** during and after increased periods of inflammation and ulceration, the body may need more calories to repair itself.
- **Side effects from IBD medications:** Some IBD medications may affect appetite and cause nausea and other unpleasant side effects, making it difficult to eat, and therefore, maintain nutrition.

Maintaining a Healthy Diet with IBD

Many parents and patients worry that something in their diet caused the child or adolescent to develop IBD. However, there is no evidence stating that specific foods can cause IBD. There is no specific "IBD diet" or medication that will cure the disease. Still, working with a GI dietitian on a specific diet plan that caters to your child or adolescent's nutritional needs could help with induction of remission, particularly in combination with medications.

In major IBD centers, pediatric gastroenterologists will usually work closely with dietitians, and caregivers, to ensure the patient is adequately meeting nutritional needs. Registered dietitians will help create food journals and decide on meals, supplements, and enteral nutrition (as mentioned earlier).

Dietary Studies

Based on symptoms and nutritional needs, the pediatric gastroenterologist and registered dietitian may recommend dietary changes for your child or adolescent. Below are a few examples of diets being studied to help in the management of inflammatory bowel disease (these are also listed in the [Resources](#) section):

- **Specific Carbohydrate Diet (SCD):** Eliminates refined and processed foods along with grains, fibers, and some sugars.
- **Mediterranean Diet:** Focuses on foods rich in fiber, as well as plant-based foods, including olive oil, low-fat dairy, herbs, and spices. Eliminates red meat and recommends poultry, eggs, yogurt, and cheese in moderation.
- **Crohn's Disease Exclusion Diet (CDED):** Includes a whole-food diet—fruits, vegetables, meats, and complex and simple carbohydrates—along with enteral nutrition (see [Nutritional Support Therapy](#) section below) designed to reduce dietary exposure to foods that may negatively impact the microbiome and the intestinal barrier.
- **IBD-AID Diet:** Avoids certain carbohydrates, similarly to SCD, that are pro-inflammatory and that may be disturbing the normal gut flora. Foods that contain lactose, wheat, refined sugar (sucrose), and corn are avoided in all phases of the diet. There are phases in this diet that allow for reintroduction of foods as the gut heals.

There are, of course, many other diets or modified versions of the above diets that GI dietitians may recommend to curb symptoms. It is always best to work with a registered dietitian who specializes in IBD for optimal coordination of dietary therapy with your child's gastroenterologist.

Nutritional Support Therapy

Because it is often difficult for pediatric patients to maintain nutritional status, nutritional support therapies have been devised to help meet the patient's nutritional needs.

Enteral Nutrition

Enteral nutrition, or EN, is a way to bring nutrition into the body to stay healthy. Enteral nutrition is usually taken in the form of a nutrient-rich formula via oral ingestion or via feeding tube. EN can either supplement caloric intake through a therapy called partial enteral nutrition, or PEN. EN can also serve as the main source of nutrition, which refers to exclusive enteral nutrition (EEN) therapy. EEN may be a first-line therapy for mild disease states.

Enteral nutrition may be used in conjunction with medications to help induce remission. Some common EN formulas available include Boost, Ensure, and Orgain. Most enteral formulas contain the protein, fat, carbohydrates, vitamins, and minerals necessary to sustain the patient nutritionally. Enteral nutrition also protects the small intestine's capability of absorbing nutrients and helping to maintain nutritional status. If deemed necessary, pursuing EN for your child will be a shared decision between the caregiver, patient, pediatric gastroenterologist, and registered dietitian. Your child's care team will help to work out a treatment plan and decide whether partial (PEN) or exclusive (EEN) nutrition should be pursued based on what the patient is able to manage.

Please note there may be psychological and social aspects to consider for children and adolescents bearing a feeding tube, so these decisions should be discussed thoroughly amongst the gastroenterologist, patient, and patient's family. It is also useful to have a GI psychologist, social worker, or mental health specialist assist in the transition to a feeding tube or oral EEN. See more in the section on [Finding a Mental Health Provider](#).



Working with a GI dietitian on a specific diet plan that caters to your child or adolescent's nutritional needs could help with induction of remission, particularly in combination with medications.

Parenteral Nutrition

Parenteral nutrition, or PN, delivers essential nutrients and calories directly into the bloodstream and bypasses the digestive tract, allowing for bowel rest during flare-ups or prior to surgery. PN uses an intravenous (IV) tube that is inserted directly into a large vein in the chest, upper arm, or neck.

When the gut is so inflamed and ulcerated that no nutrients from food are being absorbed, PN may become a viable treatment option. While EN might be a primary or supportive therapy in pediatric IBD, PN is usually more of an interim option when patients are awaiting surgery for severe complications of IBD (refractory disease, bowel perforation, stricture, fistula, etc.). It is also used to enhance nutrition prior to surgery to ensure better surgical outcomes and fewer complications. Some risks associated with parenteral nutrition include infection and blood clots. Speak to your child's provider about the risk-benefit profile of PN if you are considering it as treatment.

Avoidant Restrictive Food Intake Disorder (ARFID)

Children and adolescents living with IBD may have a higher incidence of psychological and social concerns due to poor body image, reduced quality of life, and lack of integration into school life. This psychological vulnerability may impact eating habits. Additionally, during acute flare-ups, children and adolescents may have memories of certain foods resulting in more abdominal pain and trips to the bathroom, or just general discomfort after eating. In many cultures and communities around the world, it is thought that food and diet cause IBD. Hence, children and adolescents with IBD may be put on strict elimination diets without proper supervision from a pediatric gastroenterologist and registered dietitian. As a result, fears may develop around certain foods. Pediatric IBD patients may sometimes develop a condition called Avoidant Restrictive Food Intake Disorder (ARFID), in which they manifest signs and symptoms of post-traumatic stress (PTS) around food they believe may harm their bodies. Even when the disease is in remission, patients may avoid these foods rather than focusing on reintroducing foods into their diets safely.

ARFID most often requires intervention by a mental health professional trained in gastrointestinal conditions to help unlearn these eating patterns and confront some of their fears around particular foods. It also may require the involvement of a registered dietitian who can help to reintegrate foods slowly and safely into the patient's diet. To find a GI-trained psychologist, social worker, and/or registered dietitian for your child to work with, please refer to the section on [Finding a Mental Health Provider](#).

Before eliminating foods or common allergens (gluten, dairy, etc.), it is of utmost importance to speak to a registered dietitian to rule out food sensitivities, as many children may need additional calories and nutrients from certain foods to better manage their illness.

As certain diets continue to be studied for the induction of remission in IBD, it is important to work with professionals to help manage and strike the balance in your child or adolescent's diet. The best diet is the one that meets your child's individual nutritional needs and helps them manage their IBD symptoms.

Complementary & Alternative Medicine (CAM)

There are many kinds of complementary and alternative medicine options often explored by IBD patients and their families. It is important to note that these treatments have not been extensively studied and are not proven to be effective in treating IBD. Some examples include:

- Alternative health approaches
 - Traditional Chinese medicine;
 - Homeopathy;



A physician should closely monitor a potential combination of CAM modalities with approved IBD medications.

- Naturopathy;
- Ayurveda (traditional Indian medicine).
- Mind and body practices
 - Acupuncture;
 - Massage therapy;
 - Yoga;
 - Guided meditation;
 - Tai chi;
 - Reiki.
- Natural health products
 - Herbs, such as medical cannabis;
 - Dietary supplements, such as Curcumin;
 - Probiotics.

It's important to understand that while these forms of CAM do exist, it is best if you, as the caregiver, to disclose any complementary or alternative modalities you are considering for your child or adolescent living with IBD to the pediatric gastroenterologist. It is also recommended that you coordinate with the pediatric gastroenterologist for advice and information on the interactions of these therapies with medication and/or surgery. A physician should closely monitor a potential combination of CAM modalities with approved IBD medications. Additionally, there are holistic doctors that treat patients with IBD based on alternative medicine, but, do not have the credentials to treat the disease. If you are considering using a holistic doctor, look into their credentials, as they may not be trained in gastroenterology.

It is also important to note that IBD can be a progressive disease. By solely following CAM, and not taking the therapies recommended by your child's gastroenterologist, there may be adverse effects on your child's growth, nutritional status, and disease activity.

Clinical Research

Pediatric clinical trials are important for children and adolescents living with IBD. These studies allow researchers to pinpoint the best dosage and frequency of medications in a safe and effective way in children and adolescents with IBD.

According to the Crohn's and Colitis Foundation, almost 50 percent of all medications prescribed to children and adolescents are never actually tested on them in clinical trials and are not approved by the Food and Drug Administration (FDA) for pediatric use. Many times, medications approved for adult use are used "off-label" in children; they are given at doses adjusted to the child's weight with very limited or no data showing that the medication is safe or even effective for pediatric patients.²⁵

By participating in a pediatric clinical trial, your child not only gains access to a new therapy, but they may also set a precedent for researchers to understand how certain therapies may or may not help children with IBD. Based on how your child's case fares with a trial medication, they could help shape future use of that medication in pediatric IBD care.

While there are unknown factors regarding clinical trials, research is done on the specific medication before it is offered to children and adolescents. There are many rules clinical trials must follow to limit harm to their subjects, and there is extensive care provided every step of the way. Close attention is paid to the child's disease progression during the trial, usually through regular blood work, stool studies, imaging, and scopes.

It is important to learn your child's rights in a clinical trial setting. In many cases, patients can drop out of trials if they wish to do so. Also, it is important to note that not all clinical trials have a placebo arm. A placebo is an inactive drug or treatment used to compare against the results of the actual drug or treatment, and thereby, monitor if disease status has improved.

Ask your child's gastroenterologist about clinical trials to see what might be available and if it might be an option to consider given your child's disease course, location, and other factors. You can also visit <https://clinicaltrials.gov/> to learn more.

Coordination of Care

Many times, the above-described medication regimens and surgeries allow for proactive management and treatment of severely diseased areas of the bowel. However, in Crohn's disease, there is always a risk of the disease returning despite medical or surgical intervention.

It is always best practice to coordinate care and utilize shared decision-making for proactive disease management, as described below:

- Consult a colorectal surgeon early on in your care to understand your options in order to be informed and emotionally prepared, while hopefully preventing emergency surgery.
- Coordinate care between your gastroenterologist and colorectal surgeon to optimize medical treatment before, during, and after your surgery to minimize the risk of Crohn's returning and/or worsening and of needing repeated surgeries.

In Crohn's disease, there is always a risk of the disease returning despite medical or surgical intervention. It is always best practice to coordinate care and utilize shared decision-making for proactive disease management.

Proactive Disease Management & Treating to Target

Inflammatory bowel disease can be a progressive condition in that symptoms can sometimes worsen rapidly, requiring, at times, hospitalizations and treatment escalation. It is important to manage IBD proactively in coordination with your child's gastroenterologist and other providers using shared decision-making.

The methodology behind proactive disease management involves the treat-to-target approach. This approach focuses on utilizing therapies early on and continually monitoring the levels of those medications in a patient's bloodstream in order to achieve mucosal healing and long-term remission in IBD patients—also known as **therapeutic drug monitoring**, or **TDM**. Using medications

²⁵The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/clinical-trials-community/pediatric-clinical-trials>.

that are the most effective early on, monitoring drug levels, and appropriately adjusting medication dosage can facilitate mucosal healing. Achieving mucosal healing can, in turn, lead to a longer-term remission, and thereby, reduce the occurrence of flares and the need for surgery and hospitalizations. The idea behind the treat-to-target approach is to monitor the disease proactively in hopes of improving long-term patient outcomes and reducing surgical events.

Treating to a target and therapeutic drug monitoring are particularly important in pediatric IBD because pharmacokinetics in treating children and adolescents are often different from treating an adult IBD patient on the same medication. Dosing differs between adults and children, and without as many clinical trial enrollments, it is hard to know what dosing will be optimal for a child or adolescent. Thus, proactive monitoring of drug levels becomes even more important in a pediatric setting for gastroenterologists to have a sense of whether or not a therapy is working for the patient.

It is always best to have these conversations openly with your child's physician to understand their approach and experiences with certain medications to decide on the best course of action for your child or adolescent.

Shared Decision-Making

Deciding on treatment options in pediatric IBD should be a shared decision between the family and the IBD doctor supporting the child or adolescent's care. **Shared decision-making** occurs when health professionals—IBD specialists, registered dietitians, and sometimes GI psychologists—work together with the pediatric caregiver and patient to decide upon a course of action they feel most comfortable taking to treat the patient's IBD.

In shared decision-making, care and treatment options are fully explored, and risks versus benefits are discussed. The patient and caregiver ask questions and do their own research to work with their medical team to come up with the most agreeable treatment course for the patient. Shared decision-making is often a conversation between the doctor and the caregiver of the patient during the patient's doctor's visits. As the child transitions into adolescence, the gastroenterologist begins to involve the patient in shared decision-making to help the adolescent patient understand the risk-benefit profile of treatment options themselves, and take charge of their own health. At that point, shared decision-making becomes a conversation involving the doctor, the patient, and the caregiver(s) until the adolescent is fully transitioned into adulthood and ready to take on their own care. Learn more about this in the section on [Empowering Your Child to Manage Their Crohn's Disease](#).



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WHEN SOMETHING DOESN'T GO AS PLANNED

Inflammatory bowel disease (IBD) is such a personalized disease that it's often very difficult to find a one-size-fits-all approach to patient care. Let's say your child has received a diagnosis of IBD, but, the medication prescribed is not working or quite cutting it; what do you do then?



BELOW ARE TIPS OF WHAT TO DO WHEN SOMETHING DOESN'T GO AS PLANNED IN YOUR CHILD'S TREATMENT COURSE.

If your child or adolescent is having worsening symptoms consult your pediatric gastroenterologist.

- Usually, this involves additional testing (e.g., colonoscopy, imaging, blood tests, stool studies) to see what may be causing their symptoms.
- If everything appears to be normal and your child is still having GI symptoms, there may be a chance they have a GI infection or irritable bowel syndrome (IBS), a functional GI disorder that can come hand-in-hand with IBD and can often be mistaken for IBD symptoms. It is also common for IBD patients to have a functional disorder, such as IBS.
 - If IBS is causing your child's symptoms, working with your pediatric gastroenterologist, GI psychologist, and GI dietitian can be beneficial to come up with a treatment plan.
- If testing indicates active IBD is present, please consider your child's doctor's recommendations regarding advancing or changing therapies to address the underlying inflammation.
 - This may involve increasing the dose of the medication or switching to a different type of medication. The main goal is to find the medication that helps to improve your child's symptoms, blood or stool markers, and ultimately induce mucosal healing assessed via endoscopy.
 - Trying new medications can be emotionally taxing, so it's important to involve GI psychology in your child's treatment plan at this time. It's also important to coordinate communication with the GI dietitian to ensure that all routes of care are being optimized.

Consult your child or adolescent's colorectal surgeon in case of potential surgical complications.

- If you notice a fever above 100.4°F, severe dehydration, abscess, fistula, skin lesions, and/or blood in stool after resection or ostomy surgery, it's important to reach out to your child's surgeon for immediate follow-up and examination. This could be indicative of a disease-related or surgical complication.
- Depending on the symptoms, additional testing and/or interventions may be necessary.
- Be sure to loop in your child's gastroenterologist in addition to seeking mental health care and dietary interventions, if suggested by your child's care team.

Please refer to the section on [When to Contact Your Provider](#) for additional details.

Seeking a Second Opinion

Sometimes patients and families want to make sure they are making the right decision and may seek a second opinion to help them to do that. Seeking a second opinion may also be helpful if it starts to become clear to you that the diagnosis may not be correct or that your child's condition is worsening under the current care plan. If you are trying to distinguish between ulcerative colitis and Crohn's disease, and/or prescribed medications or surgery haven't resolved your child's symptoms or inflammation, it may be worth considering a second opinion. It's important to note that some patients and caregivers seek a second opinion before starting a new medication or while considering surgery for their child's IBD to ensure they are making the best medical decision for them.

So how does one seek a second opinion? Sometimes your child's current team will recommend a second opinion and refer you to a colleague for your peace of mind. Other times, it will be important to refer back to the section on [Finding the Right Provider](#).

Remember that second opinions can be for medical care or surgical care and it may be important to get different perspectives on how to manage your child's disease particularly if their case is becoming more complex. If both your child's current team and the second opinion are recommending the same or a similar treatment plan, then the decision is easy to move forward with the plan that they are both suggesting. When the second opinion differs from the current care team's plan, that's when informed decisions may need to be made regarding what course of action to follow and if you would like to switch your child's care elsewhere.

If you are planning to stay with the current care team, you should be open with the medical team about seeking a second opinion out of respect for the professional, but also for the second opinion to be openly discussed and weighed on carefully with the current care team, should it differ from their plan of action. Ultimately, this is a shared decision and needs to be guided by one care team or another.

If you do end up switching your child's care, remember to make sure all medical and surgical records are transferred to the new office and that all medication approvals and prescriptions for medical devices (e.g., ostomy supplies, etc.) are also transferred under the new physician's name to allow for a seamless continuity in care.

Leveraging Reputable Patient Support Systems & Organizations

There is a plethora of information available about IBD online. However, discerning between credible sources and misinformation is very important to ensure that you and your child have the best information possible to make the decisions relevant to your child's care.

The information you and your child should start off with is always the medical advice given by your child or adolescent's care team. Doing your own homework is, of course, very important. However, it's even more important that you don't get lured into any negativity or misinformation that is being spread online. There are many credible patient advocacy groups in the GI space, including, but not limited to the Crohn's and Colitis Foundation, ImproveCareNow (ICN), the United Ostomy Associations of America (UOAA), and the International Foundation for Functional Gastrointestinal Disorders (IFFGD). The Crohn's and Colitis Foundation and ICN put out detailed information around inflammatory bowel disease; however, ICN's primary focus is supporting and empowering

Doing your own homework is, of course, very important. However, it's even more important that you don't get lured into any negativity or misinformation that is being spread online.

pediatric IBD patients and caregivers, whereas the Crohn's and Colitis Foundation provides support and research on patients of all age groups living with IBD. The UOAA focuses on ostomy-related content, including ostomy surgery done as a result of persisting IBD. The IFFGD has some coverage of IBD, but mostly focuses on functional GI ailments (irritable bowel syndrome, gastroparesis, small intestinal bacterial overgrowth, etc.), which may be comorbidities of IBD itself.

Additionally, the American Gastroenterological Association (AGA) and the North American Society For Pediatric Gastroenterology, Hepatology & Nutrition (NASPGHAN) work with clinicians, researchers, and patient advocates in the GI field to put out very credible information and studies to improve care and consider ways to move the needle on GI treatments. NASPGHAN focus is primarily pediatric GI ailments in North America, whereas the AGA focuses on putting out reliable information to physicians of all patients with GI conditions.

This pediatric IBD guidebook, developed by the National Alliance for Caregiving (NAC), is a credible resource in that it is a culmination of the work and research done by doctors, surgeons, mental health practitioners, and patient experts.

In order to ensure that a resource is credible, it's important to consider the following:

- Who are the authors? Are they respected and well-known in the field? What are their credentials?
- Is the source reputable? Is the article published on a reputable, non-biased website, or in a peer-reviewed scholarly journal?
 - If a patient advocate is publishing on their blog, are they a reputable expert in the disease area? Are they interviewing reputable experts on their blog? Do they work with any of the patient advocacy groups listed above?
- Is the information relevant or pertinent to your child's care?
- Is there supporting documentation (graphs, charts, illustrations, etc.)?
- Are there legitimate sources referenced to back up any claims made?

All of this said, please make sure you are verifying any information learned in online support groups and/or social media chatrooms for IBD patients and caregivers. There are many patients and caregivers participating in these groups sharing a wide variety of viewpoints on all aspects of the disease; it is therefore possible for misinformation to spread very easily and it's imperative to be able to distinguish credible information from misinformation.

For your ready reference, there is a list of credible resources handpicked by the National Alliance for Caregiving and the authors of this guidebook listed at the end of this manual, in the [Resources](#) section.



HEALTH MAINTENANCE, SUPPLEMENTATION, & VACCINATION

Health Maintenance

In addition to proactively managing a pediatric IBD patient's disease, overall health maintenance is critically important to stay on top of and address as a caregiver. Health maintenance includes growth—in terms of height and weight—pubertal development, vaccination status, and surveillance of disease activity, in addition to monitoring the following: vitamin and mineral supplementation, dietary changes, and the psychological and social impact of the disease on the patient. Even in remission, health maintenance is an aspect of disease management that must continue throughout the course of your child or adolescent's disease journey.

Growth & Nutritional Status

Stunted growth, poor weight gain (low body mass index), and delayed pubertal development can all be signs of poor control of disease activity. If these are symptoms you recognize in your child, it's time to speak to your child's gastroenterologist about checking on disease activity and adjusting or readjusting medications and/or dietary therapies accordingly. Remember that mucosal healing and remission are primary goals in disease management and working to achieve remission will help to ensure your child's growth and proper sexual development into adolescence and adulthood.

Bone Health

As caregivers, it's important to pay close attention to bone health in the case of young IBD patients. Bone formation can be adversely affected through a combination of nutritional deficiencies, physical inactivity, inflammatory processes, and corticosteroid use. It is important for pediatric patients to have a DEXA (bone density) scan done upon diagnosis as a baseline, especially if the patient has been on steroids or if the patient has experienced severe malnutrition to ensure there is no development of osteopenia (the beginnings of the loss of bone mass) or osteoporosis (loss of bone mass and low bone density) particularly from steroid use. A specialist may become involved in ensuring both bone and joint health, as many patients also complain of joint pain with IBD. There are supplementation strategies to help maintain bone health as described in the [Supplementation](#) section.

Skin Health

As mentioned in the [Extraintestinal Manifestations and Comorbidities](#) section, there is also a risk of skin lesions developing in IBD. Additionally, there are concerns around an increased risk of skin cancer especially if your child is on combination therapy (biologic and immunosuppression) or on anti-TNFs. It is thus recommended that your child or adolescent wear sunblock with an SPF greater than 30 and avoid prolonged exposure to the sun. An annual skin screening is also recommended. It is best to initiate care with a dermatologist to help your child or adolescent maintain optimal skin health with IBD.

Eye Health

Also mentioned in the [Extraintestinal Manifestations and Comorbidities](#) section is the development of eye issues in IBD. It is important for your child or adolescent to have routine visits annually with an optometrist and ophthalmologist to ensure that their eye health is optimal. If your child or adolescent is experiencing eye pain, redness, swelling, blurred vision, etc., you should follow up with an ophthalmologist who can treat eye conditions that may be related to IBD.

Mental Health

While gastroenterologists do regularly screen for changes in mood, behavior, and appetite, as well as degree of interest in and performance in school, sports, hobbies, etc., it is important for the caregiver(s) or their child to highlight any changes in mental health status to their child's care team. This allows your child's gastroenterologist to get the IBD center's mental health practitioner involved. In the event there is no access to a mental health provider, your child's doctor may be able to refer your child to an external mental health provider. Please refer to the section on [Finding a Mental Health Provider](#) for further details on how to locate a provider.

It is important for the caregiver(s) or their child to highlight any changes in mental health status to their child's care team.



Prevention of Colorectal Cancer & Proactive Disease Monitoring

With IBD, there is a risk of colorectal cancer (CRC) particularly after 8-10 years of living with Crohn's disease or ulcerative colitis. Moreover, it is recommended that your child's gastroenterologist keep regular check on your child's colorectal health and disease activity. It is thus important to screen for CRC and monitor IBD activity through a colonoscopy every 1-3 years, or as recommended by your child's physician.

Please discuss the appropriate timeframe for screening with your child or adolescent's gastroenterologist, as this may be specific to disease activity among other considerations.

Tuberculosis Screening

Tuberculosis (TB) is an infectious disease that mainly affects the lungs. The bacteria that cause tuberculosis are spread from one person to another through tiny droplets released into the air via coughing and sneezing.

TB screening is important, especially prior to the initiation of immunosuppression and/or the use of biologics. The concern around TB is that anti-TNF agents, specifically, can reactivate a latent case of TB. Regular screening may also be important to check if a patient on biologics has been exposed to TB locally or via travel to a country where TB is endemic.

Screening is usually done via a skin test called PPD (purified protein derivative) and/or, more recently, the Quantiferon Gold test, which can be done as a blood test to check if an IBD patient has TB.

Supplementation

Nutritional supplements may be important especially for pediatric patients living with IBD in preventing deficiencies and malnutrition. Due to disease flare-ups, surgeries, and other complications, it may sometimes be difficult for patients to get enough nutrients. As such, it is generally advised by GI dietitians and pediatric gastroenterologists to get baseline bloodwork on vitamins and minerals in addition to the usual blood tests done for IBD. From the blood test reports, the gastroenterologist and/or dietitian can make recommendations on how best to either supplement and/or increase intake through dietary changes to reduce nutritional deficiencies.

Below are some supplements that are commonly recommended for IBD patients:

- **Calcium** maintains a child's bone and dental health. It is recommended for all IBD patients.
 - Calcium is especially necessary if your child is on corticosteroids, has osteopenia, or has osteoporosis.
 - Calcium is most effective when it is taken with vitamin D.
- **Vitamin D** helps the body absorb calcium. It is recommended for all IBD patients.
 - Some studies have shown that vitamin D helps control inflammation.
 - Vitamin D is best taken with calcium to help enhance absorption.
- **Magnesium** is important for many processes in the body, including regulating muscle and nerve function, blood sugar levels, and blood pressure, and making protein, bone, and DNA.
 - Deficiencies in magnesium can occur during severe flare-ups and bouts of diarrhea.
- **Potassium** is an electrolyte vital for the functioning of all cells, tissues, and organs in your body.
 - Deficiencies in potassium can occur during or after a course of prednisone or if the patient suffers from chronic diarrhea.
- **Iron** is a part of hemoglobin, which is found in red blood cells and carries oxygen throughout the body. Inflammation and rectal bleeding from intestinal ulcers can result in iron deficiency, which can lead to anemia.
 - Instead of iron pills, many GI doctors recommend iron infusions, as oral iron supplements can have a pro-inflammatory effect and abdominal pain.
 - It's important to have iron levels tested before beginning supplementation, as excess iron can result in liver toxicity.
- Foods high in iron should be paired with a vitamin C rich food to enhance absorption.
- Some multivitamins, especially those that are in gummy form, do not have iron, so be sure to pay attention to the label if using a multivitamin to make sure that it contains iron.
- **Vitamin B12** helps maintain the health of nerves and blood cells. B12 is absorbed in the terminal ileum, which is located at the end of the small intestine.
 - Crohn's patients with ileal disease activity (or surgery to remove the ileum) may have issues absorbing B12 from food.
 - Vegans and vegetarians are also at risk for developing vitamin B12 deficiency.
- **Folic Acid** (Vitamin B9) helps the body produce and maintain new cells while helping to process fats and carbohydrates.
 - Some medications prescribed to treat IBD, including sulfasalazine and methotrexate, may interfere with folic acid absorption.
- **Vitamins A, C, E, and K** are essential for cell production and preventing cell damage, fighting infections, and maintaining bone health.
- **Zinc** helps the body fight off infections. The level of zinc in the body may be affected by active IBD, including severe diarrhea, short bowel syndrome, and extensive disease in the small intestine.

Please always talk to your child's care team before adding any supplements, including herbal and complementary therapies.

- Some supplements can cause gastrointestinal symptoms, including nausea, vomiting, bloating, and diarrhea.
- Check the ingredients on each of your child's supplements for artificial colors, sugar alcohols, milk products, or preservatives, all of which may aggravate IBD.
- Many supplements should be taken with food and not on an empty stomach to avoid irritation.

One thing to keep in mind is that certain supplements can tax the liver and may result in liver damage over time. Please do not have your child take supplements without your child's gastroenterologist's input.

Always remember what works for one patient may not work for everyone. Check with your child's healthcare providers before starting any supplements, as they may need proper dosing and monitoring.

Vaccinations

Vaccines are routinely given to protect children against many infectious diseases. They work to help the body develop antibodies to certain bacteria and viruses. In the case of children or adolescents living with IBD, it can be important to be vaccinated against infectious diseases in order to prevent infection, as infections may lead to flare-ups and/or overall exacerbation of IBD.

Children and adolescents living with IBD are generally recommended to receive vaccines on the same schedule as other children. However, because corticosteroids, immunosuppressants, biologics, and small molecules all suppress and modify the immune system to help treat IBD, this can sometimes alter the child or adolescent's response to a particular vaccine; if the immune system is suppressed, the body may not form enough antibodies after a vaccine is given to fight off a disease.

The other consideration is that patients on immunosuppression of any kind may not be able to receive live, attenuated vaccines and should opt for inactivated vaccines instead. Live, attenuated vaccines contain the active virus, but, in a weakened state; inactivated vaccines also contain the virus, but, in a dead state. In healthy immune systems, live, attenuated vaccines allow the body to create antibodies by fighting off the virus. In patients on immunosuppression, live vaccines may end up causing the viruses they are intended to prevent in patients as the immune system may not be able to adequately fight off the virus and develop antibodies to it. The only live vaccines that are recommended are those for Measles, Mumps & Rubella (MMR) and Varicella. These are generally administered to individuals before they're diagnosed with IBD, since they are given at a young age. If your child needs to receive a live virus vaccine, it should generally be administered at least one month prior to starting immunotherapy.

It's important to note here that family members who are in close contact with a child or adolescent who is taking immunosuppressants for their IBD can also easily pass on an infectious disease to them should they be sick or receive a live virus vaccine. Please always take extra caution to isolate if sick or receiving a live vaccine and please speak to your child's gastroenterologist regarding these concerns should they arise.

There are certain vaccines that may be recommended for foreign travel (e.g., family vacations, study abroad, etc.). Different destinations may require different vaccines and it's important to check the CDC website at <http://www.cdc.gov/travel> to know what vaccinations your child may need. Please also discuss vaccines for foreign travel with your child's gastroenterologist to ensure they're safe to receive (especially in the event that they are live virus vaccines, such as the smallpox, typhoid, and yellow fever vaccines).

Regarding any new vaccines or vaccines in development, please speak to your child or adolescent's gastroenterologist regarding specific recommendations.

Many families may be nervous to get a vaccine or to vaccinate their child. To find credible information on vaccines, visit <https://www.cdc.gov/vaccines/parents/why-vaccinate/vaccine-decision.html>.



Regarding any new vaccines or vaccines in development, please speak to your child or adolescent's gastroenterologist regarding specific recommendations.



OVERVIEW OF CHILDHOOD VACCINES

Measles, Mumps & Rubella (MMR): *These are all live virus vaccines and are not recommended for anyone on biologics or immunosuppression. These are recommended for children at approximately age 1 and again between ages 4-6. MMR should be given prior to the initiation of immunotherapy for IBD. Most patients would have received this prior to being diagnosed.*

Diphtheria, Tetanus & Pertussis (Tdap, whooping cough): *Tdap is a part of a routine series of vaccinations given to children and are not live vaccines. They may be given safely to children and adolescents living with IBD. It is also recommended that all adolescents receive a booster shot at the age of 11-12.*

Varicella (chicken pox): *The chicken pox vaccine is a live virus vaccine and is usually given at approximately age 1. As a parent of a young child with IBD, it may be best to ask your child's gastroenterologist about being immunized prior to starting any form of immunosuppression.*

Hepatitis A & B: *The hepatitis vaccines are not live virus vaccines. An infant receives three doses of Hepatitis B vaccine in the first year of life. Hepatitis A vaccine is also recommended for children and is given in two doses usually during the second year of life.*

Haemophilus Influenzae: *This is not a live vaccine. Children under the age of 5 receive four doses of this vaccine. It protects against serious illnesses, such as meningitis and throat infections.*

Meningococcal: *The meningococcal vaccine is recommended for children at approximately 11 or 12 years of age. This vaccine protects against meningitis and, in the past, was recommended for students entering college, as this bacteria can spread in dorms and other close living conditions.*

Influenza: *The injectable form of this vaccine is not a live vaccine. However, the nasal form is a live vaccine and should not be given to children or adolescents on any form of immunosuppression. Children over 6 months of age should be vaccinated yearly.*

Pneumococcus: *This is not a live vaccine. The vaccine is usually administered to children in four doses. It protects against illnesses caused by the bacteria streptococcus pneumoniae, such as pneumonia and meningitis.*

Pneumovax 23: *This injectable vaccine protects patients against bacteria called pneumococcus. It is usually given to people with a chronic condition or older adults who are at risk for serious pneumococcal disease. This vaccine is usually only given to adults, so pediatric offices often don't carry this. Talk to your child's provider to learn more about this vaccine.*

Polio: *The injectable polio vaccine is advised for children as it is not a live virus, and will not cause polio. The oral form is a live vaccine and is not considered safe for people who are on immunosuppressants.*

Rotavirus: *This is a live vaccine given orally. Rotavirus is a highly contagious infection and the vaccine should be given long before initiation of any immunosuppression. Rotavirus causes severe, watery diarrhea, abdominal pain, fever, loss of appetite, and dehydration. It is also known to exacerbate IBD and trigger flare-ups, so this is an important vaccine for your child to have early on.*

Human Papillomavirus (HPV): *The HPV vaccine is generally recommended for children above age 11. It is not a live vaccine and protects against HPV-related infections and cancers. This vaccine is usually given in two-three doses.*



COST OF CARE AND ACCESS

Contributors to this section include: Mousumi Bose, Assistant Professor, Nutrition and Food Studies, Montclair State University; Theresa J. Smith, AS, LPN, CCRC, Advance Directives Research Project Coordinator, Department of Humanities, Pennsylvania State College of Medicine; Field Nurse, Bayada Pediatrics; Kimberly Haugstad, CEO, ACTION Partners, LLP; Co-founder, Upequity.

Caregiving for a child with IBD often impacts family finances. The National Alliance for Caregiving's 2019 report, *Riding the Roller Coaster of Inflammatory Bowel Disease*,²⁶ found that almost two-thirds of caregivers reported cutting down their spending on various items or activities. In addition, more than a third of caregivers reported they stopped saving, took on personal debt, and used up personal savings; more than one in five reported they'd paid bills late.

Beyond the costs of medical care, the impact that IBD has on the income for the family is significant. Nearly all participating caregivers who worked outside the caregiving relationship (94 percent) in the *Riding the Roller Coaster of Inflammatory Bowel Disease* study reported missing time at work because of caregiving, and more than half of working caregivers reported declines in their level of performance or productivity (55 percent). It is not uncommon for a caregiver to make career changes to be able to manage the medical appointments, medical needs, and daily care necessary for a child. A substantial number of IBD caregivers also reported taking a leave of absence, dropping from full- to part-time or cutting back on work hours, and turning down a promotion. Nearly 10 percent reported that they either gave up working entirely or lost job benefits.²⁷ These options come with high costs that can financially devastate a family.

There are many public and private programs and resources that may be accessible to assist families with the financial cost of caring for a child with Crohn's disease.

It is not uncommon for a caregiver to make career changes to be able to manage the medical appointments, medical needs, and daily care necessary for a child.



Having insurance coverage is important to families managing Crohn's disease. Understanding your insurance is also very important.

Medical Insurance

Having insurance coverage is important to families managing Crohn's disease. Understanding your insurance is also very important. Patients and caregivers living with Crohn's disease tend to be empowered, knowledgeable, and engaged by necessity. The reality is that your insurance company may not be familiar with your child's disease or its treatment. You and your doctor may need to educate them on what your child needs. When needed, doctors help navigate exclusions and exceptions. Learning to navigate insurance may seem like learning a whole new language, but many resources exist to help. Always carefully review insurance plans before signing up for coverage. Resources you may want to reach out to for guidance include:

- Family or friends who have chronic conditions;
- Your employer's human resources;
- Directly to the insurer (your child may be assigned a case manager);
- Nurses, social workers, and case managers from hospital centers;
- Patient advocacy organizations that provide education and support.

²⁶National Alliance For Caregiving. (2019). *Riding the Roller Coaster of Inflammatory Bowel Disease: A National Study of Caregivers of Individuals with Crohn's Disease or Ulcerative Colitis*. https://www.caregiving.org/wp-content/uploads/2020/05/September-2019_National-IBD-Caregiving-Report_digital.pdf ²⁷Ibid.

Premium and Co-Pay Assistance

There are numerous copay and coverage assistance programs offered by pharmaceutical manufacturers and foundations that exist for many conditions that help families with premium and co-pay assistance to help offset patient out-of-pocket costs. Not all diseases are covered, and some funds close during the year when funding is exhausted, so it is necessary to review each to see if your child's disease is supported by the organization.

Copay and coverage assistance programs include:

HealthWell Foundation

www.healthwellfoundation.org

Assists with copays, premiums, deductibles, and out-of-pocket expenses.

Good Days

www.mygooddays.org

Provides resources for life-saving and life-extending treatments to people in need of access to care.

The National Organization for Rare Diseases (NORD)

www.rarediseases.org

Provides financial assistance for medications, insurance premiums and co-pays, diagnostic testing, and travel for clinical trials or consultation with disease specialists.

Patient Advocate Foundation

www.patientadvocate.org

Provides case management assistance for the uninsured or underinsured with life-threatening or debilitating illnesses. Includes access to care; co-pay assistance; social security disability applications; and insurance appeals.

Patient Services, Inc.

www.patientservicesinc.org

Assistance programs for various conditions. Programs include help with co-payments, premiums, ancillary services, infusion, nursing services, or travel.

There are numerous copay and coverage assistance programs offered by pharmaceutical manufacturers and foundations that exist for many conditions that help families with premium and co-pay assistance to help offset patient out-of-pocket costs.

Supplemental Security Income

SSI payments for children with disabilities are monthly supplements to people with low income and limited resources. If a child is younger than 18, they may qualify if they have a medical condition or combination of conditions that meets Social Security's definition of disability for children and if their family's income and resources fall within the eligibility limits. The amount of the SSI payment is different from state to state. Your local/state Social Security office can provide more information on how to apply.

Social Security Disability Insurance (SSDI)

SSDI benefits are for adults who have been disabled since childhood. This benefit is paid based on a parent's Social Security earnings record. To be eligible, a parent must be receiving Social Security retirement or disability benefits or have died, but worked enough to qualify for Social Security. SSDI benefits continue as long as the individual remains disabled, although marriage of the disabled adult may affect eligibility for this benefit. Find out more at www.ssa.gov/disability.

Medicaid Waiver Programs

Medicaid waiver programs are state-run programs that use federal and state funds to pay for health care for people with certain health conditions. The process for a Medicaid waiver will vary depending on the specific waiver and the state of residence. Most states have some type of Medicaid waiver program and there are many waiver types. Find out more at www.medicaid.gov.

Children's Health Insurance Program

CHIP is an insurance program for low-cost health coverage to children in families that earn too much money to qualify for Medicaid but not enough to buy private insurance. In some states, CHIP covers pregnant women. Each state offers CHIP coverage and works closely with its state Medicaid program. You can apply any time. If you qualify, your coverage can begin immediately, any time of year. Learn more at www.healthcare.gov/medicaid-chip/childrens-health-insurance-program.

Government Support and Resources

There are state and federal programs that can assist you in caring for your child, such as Medicaid, Medicaid Waivers, Children's Health Insurance Programs, or other supplements or support. The Benefit Finder can help identify what benefits your child may qualify for: www.benefits.gov.



There are organizations available to assist with managing finances or providing support.

Title V Funding and Catastrophic Illness Relief Funds

Several states use federal funding from the Title V Maternal and Child Health Services Block Grant Program to support the promotion and improvement of the health and well-being of children with special needs and their families. One example of some programs that utilize this funding are catastrophic illness relief funds. The purpose of catastrophic illness or health relief funds is to help ease the burden of out-of-pocket health care expenses that are not covered by insurance. The financial support that is given to caregivers may be taken from state or local funds. Catastrophic Illness funds vary from state to state. Examples of state websites for Catastrophic Illness Relief Programs are listed below.

- Title V funding: www.mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program. Click this link to find the phone number to call for the state you live in.
- Catastrophic Illness in Children Relief Fund in New Jersey: a financial assistance program for New Jersey families with catastrophic medical funds relating to a child's illness or condition. www.state.nj.us/humanservices/cicrf/home/.
- Catastrophic Illness in Children Relief Fund in Massachusetts: a financial relief for Massachusetts families caring for children under the age of 22 with large medical and related expenses. www.mass.gov/catastrophic-illness-in-children-relief-fund-cicrf.

Other Financial Resources

Even if your family has medical insurance and other financial support, a serious medical issue or disability can result in high medical bills. The loss of income, or other miscellaneous expenses, such as food, travel, or other medical needs adds up quickly. There are organizations available to assist with managing finances or providing support.

Medication Assistance

Needy Meds

www.needymeds.org

Information about government programs, low-cost or free medical and dental clinics, and prescription assistance and disease-specific financial aid programs.

RxAssist

www.rxassist.org

Offers a database of patient assistance programs, as well as practical tools, news, and articles for health care professionals and patients.

National Alliance on Mental Illness

www.nami.org

National Alliance on Mental Illness (NAMI) has compiled a list of free or low-cost mental health medications provided by pharmaceutical companies.

Online Fundraising

Also known as crowdfunding, this is a method that can be considered when faced with financial hardship because of Crohn's disease. Some patients find that friends, family, coworkers, and community members are eager to contribute financially if they are aware of your difficult situation. Money can be raised for many purposes, such as emergency support, equipment, or supportive needs, such as to fund research. Sites like GoFundMe, Kickstarter, Fundly, 99Pledges, or Facebook are used commonly in crowdsourcing.



CARE COORDINATION, MEDICAL TASKS, ACTIVITIES OF DAILY LIVING

Contributors to this section include: Mousumi Bose, Assistant Professor, Nutrition and Food Studies, Montclair State University; and Kimberly Haugstad, CEO, ACTION Partners, LLP; Co-founder, Upequity; Theresa J. Smith, AS, LPN, CCRC, Advance Directives Research Project Coordinator, Department of Humanities, Pennsylvania State College of Medicine.

There have been many research and treatment advances in recent years for Crohn's disease.²⁸ However, it can be a difficult journey getting an accurate diagnosis and finding doctors with the right expertise to help you navigate your child's ongoing care and treatment. There is no cure for Crohn's disease, but as research, science, and technology continue to advance, there is hope. Symptom management is an important part of care, and the goal of most care plans. For more information on symptom management, treatment, and remission, check out the previous section on [Understanding Symptoms, Flare-Ups, and Remission](#).

There can also be numerous challenges to accessing care and therapies. Some specialty care may be accessible at only certain hospitals and drugs at certain pharmacies. Insurance companies vary widely in their in-network decisions and covering the cost of drugs. Prior authorization processes with an insurance provider, which reviews if a medication is appropriate for therapy, can be confusing and take time to process. All of these aspects of care management can be challenging, especially for families unused to managing IBD, but you have an important voice in the care of your child.

Defining Your Role on the Care Team

As the primary caregiver, you are an expert on your child's specific needs and typically will be the very best advocate for your child. Decision-making is not a purely objective process. There are subjective perspectives that go into clinicians' choices for treatment, and both the patient and caregiver should be empowered to share their perspectives. The caregiver notices small things about the patient's condition that the patient might forget to mention, such as their mood, what they ate, etc. Most caregivers of children and adolescents with Crohn's disease live with their care recipient. They are thus living with the disease every day, just as the patient is.

With that, it's important to understand your role on the care team and to communicate that with your child's doctor(s) and clinician(s).

The way in which doctors and clinicians include you in the care team may change as your child gets older. For very young patients, doctors and clinicians may solely rely on you, the caregiver, for information on your child's symptoms and everyday experiences with Crohn's. However, as a supportive decision-maker, it's important to remember that you play a role in ensuring that your child's voice is heard at the doctor's office. By encouraging your child to speak up and ask questions, your child's doctor or clinician should learn to see the patient, no matter how young, as an active part of the care team. As your child gets older, their doctor may be more hesitant to allow you to accompany your child to appointments and/or to play an active role in decision-making. In these situations, have regular discussions with your child about how they want you to be involved in their care, and communicate this together to your child's doctor(s) and clinician(s). For example, if your child still wants you to join them for doctor's appointments, make that clear to the doctor and advocate to be a part of appointments, even if it means just being present for support and not participating in discussion. If your child no longer wants you to join them, respect their decision, but make sure that you are still communicating information for you to be able to play your role as a shared decision-maker or care partner.

Supportive Decision-making

Supportive decision-making refers to the model of care in which formal and informal caregivers support the care recipient in participating in decision-making.²⁹ This concept is especially relevant for children and adolescents with Crohn's disease who may not be viewed as "old enough" or "mature enough" to take part in important decisions that impact their health. However, children and adolescents have a right to make choices about their bodies, and they also have a right to learn to be prepared to make those decisions on their own when they are adults. Caregivers of children and adolescents with Crohn's disease should take on the role of supportive decision-maker to ensure their child's voice is heard.

Shared Decision-making

Caregivers can also play the role of shared decision-maker. Though children and adolescents have a right to take part in decision-making for their health, caregivers and parents are also experts on their children's health and have a role to play in decision-making, as mentioned above. Caregivers, patients, doctors, and other specialists can share decision-making by collaborating through their different expertise on the patient's disease. As your child gets older, especially from childhood to adolescence and adolescence to young adulthood, it's important to have regular discussions about the specific ways in which your child wants you to be involved in shared decision-making.

²⁸The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/news/5-major-advances-ibd-treatment>. ²⁹Autism Spectrum News. Retrieved from <https://autismspectrumnews.org/how-supported-decision-making-can-help-family-caregivers/>.

Finding Quality Medical Care Providers, Hospitals, and Medical Centers

Getting quality care means receiving the right care, treatment, and support at the right time. It is not unusual to have follow-up care appointments with your specialist regularly in addition to urgent care needs. To get the best possible outcomes, care should be coordinated. That means doctors, nurses, laboratories, radiology services, specialty services, genetic counselors, geneticists, therapists, nutritionists, and hospitals need to be working together. Great care includes these medical providers working as a united team to provide the best care they can in the most cost-effective and timely way. If providers are not talking to each other, your child may be subjected to unnecessary tests, medication errors, or costs. Communication is vital.

Unfortunately, the American healthcare system is highly fragmented. Many doctors and medical providers believe deeply in coordinated care and are working to bring the system together. However, today, it can also fall to you as a caregiver to be a strong, determined, and dedicated advocate for your child to bring this type of coordinated care together. This is particularly true if your child is seeing many medical providers across multiple clinics and hospitals. Patient organizations are well familiar with these challenges and can be a great support resource to help educate you in how to successfully do this.

Healthcare and treatments can change rapidly. Keeping up to date on the latest care and therapies is important and can be a challenge for busy doctors. Doctors and specialists who work as groups find it to be a positive way to keep current on new treatment and research. Technology and technology-sharing, such as electronic medical records and interactive websites, provide education to you as well as to medical providers and result in better care and treatment.

Never forget, your opinion does matter. A quality clinic will ask for feedback on the care and services received. Areas for change you identify through this feedback can help the clinic improve and ultimately serve your child better.

The Crohn's and Colitis Foundation offers a list of experts in Crohn's and ulcerative colitis across the nation, from surgeons to dieticians and mental health providers. To search for an expert in your area, check out the webpage 'Find a Medical Expert' on the Crohn's and Colitis Foundation website, or check out our [Resources](#) section for the link. In specialty areas, medical doctors are also often researchers and may be conducting clinical trials that may need study participants. The Crohn's and Colitis Foundation also provides information on clinical trials your child may be able to participate in. Check out the [Resources](#) section for the link to this information.



Checklist to Consider when Looking for a Healthcare Team³⁰

- Doctors and centers caring for your child have access to medical records including information about medications, labs results, urgent care visits, after hours calls, etc.;
- A coordinated care team exists with doctors, specialists, and other medical providers;
- Commitment to good communication between all medical providers that care for your child's condition exists;
- Health care services, such as X-ray and imaging, lab, specialty, or education services are at or nearby the child's medical center;
- Ongoing preventive care and clear treatment instructions are provided;
- Doctors or specialists keeps themselves up to date on the latest in medical advancements and research being done;
- A backup doctor or specialist is available when a primary doctor is not. This provider has access to the child's medical records and history;
- Medical providers hear, listen, and answer your questions and concerns;
- Medical providers help you make informed decisions by discussing the pros and cons of various care and treatment options;
- You have access to medical advice and guidance 24 hours a day;
- You have easy access to medical records and lab test results online.

<https://accountablecaredoctors.org>

³⁰The Council of Accountable Physician Practices: An affiliate of the AMGA foundation. Retrieved from <https://accountablecaredoctors.org>.



Building A Medical Care Team

Finding knowledgeable specialists and learning to make informed treatment decisions while taking care of your sick child is a big role. Know that you are not alone. Your child's care team may include many specialists and additional medical care providers.

Treating Crohn's disease involves a range of services including assessment, diagnosis, care, treatment, testing, support services, and in-patient care. It is helpful to have a primary person to communicate with on the team whom you feel comfortable with and who understands your child and your family's needs. This is often your case manager or nurse coordinator. When you build a meaningful, trusting relationship and find solutions together, positive outcomes follow.

The following are typical medical providers that may be a part of a core care team.

Pediatrician

Generalist medical doctor who manages the physical, behavioral, and mental health for children until age 18.

IBD Specialist

A doctor that has advanced training and experience in a specific field of medicine. Often these doctors are also involved in clinical research.

Clinical Geneticist

A doctor who meets with patients to evaluate, diagnose, and manage genetic disorders and has special training in genetics.

Nurse Coordinator

Often, a nurse coordinator who works directly with a specialist doctor or clinic will be a primary and important contact and resource. This nurse supports communication among a child's care team.

Pediatric Dietician

Pediatric dietitians are responsible for assessing and coordinating food choices that benefit children and adolescent's different health circumstances.

Case Manager

A case manager can help you manage many aspects of your child's care. This may include coordinating providers and services or addressing insurance issues. Often these are social workers or nurses. You may find a case manager through your child's hospital, social services, or insurance provider at no cost. Case managers can be hired privately.

Social Worker

Social workers can have different roles, depending on the setting. In hospital or healthcare settings, they can assist with locating resources, completing paperwork, and many other tasks, as well as providing emotional support. Licensed Clinical Social Workers (LCSW) are qualified to diagnose mental health conditions and provide psychotherapy. You may locate an LCSW in the hospital or university where your child's medical provider works, or in private practice.

Clinical Psychologist

A licensed doctoral level professional trained to evaluate mental health status using clinical interviews, psychological evaluation, and testing. Psychologists are qualified to diagnose mental health conditions and provide psychotherapy. Clinical psychologists serve a similar function to social workers, but use psychological testing for mental health evaluations.

Genetic Counselor

Genetic counselors have specialized education in genetics and counseling to provide personalized help to families as they make decisions about genetic health.

Pathologist

A medical healthcare provider who examines the causes and effects of diseases, especially for diagnostic purposes.

Radiologist

Medical doctors that specialize in diagnosing and treating diseases using medical imaging.

Hospitals and IBD Centers

IBD centers can greatly benefit patients with Crohn's disease by providing collective expertise and access to patients. These centers bring doctors and their collective experiences together and patients are able to get the high-quality care they need. These centers also allow caregivers to connect and share experiences, information, and advice with each other. For patient families, both the convenience of specialists working together and sharing their expertise are significant benefits. In addition to medical care, these clinics play an important role in educating you and your child about their disease. They often work closely with patient advocacy groups and promote public awareness of a specific disease or disease area. ImproveCareNow offers an interactive tool to search for IBD care centers by location. Check out our [Resources](#) section for the link.

Collaboration Across Professionals

You will likely need to interact with multiple healthcare professionals, specialists, and agencies in the management of your child's health care. Results from our national study, as well as caregiver listening sessions conducted in the summer of 2020 show that coordination of medical care for a child or adolescent with Crohn's disease often falls on the caregiver. This can take a toll on you as a caregiver, especially when considering the numerous other tasks associated with caregiving.

To address this, you can work with your child's medical care providers to develop a care coordination plan for your child. According to the Agency of Healthcare Research and Quality, care coordination consists of deliberately organizing patient care activities and sharing information among all of the stakeholders in a patient's care to achieve safer and more effective care. A care coordination plan may involve:

- Setting up a schedule for health care provider visits, medications, and/or treatments;
- Providing resources in finding local services or providers;
- Referrals to specialists or other health care providers, community resources, and case managers who can assist in finding care and services;
- Getting approvals for care or services;
- Helping coordinate care among various providers.

Implementing a care coordination plan may be an effective strategy for you in helping improve your child's outcomes and empowering you as a caregiver to be part of the decision-making process in your child's care management.

When Access to an IBD Center Isn't Available

IBD centers have a beneficial interdisciplinary care model, but most people in this country don't have access to an IBD center due to various reasons, including location and insurance challenges. Patients and caregivers sometimes need to "piece together" their care team.

Because certain medications to treat your child's Crohn's disease may cause side effects on other aspects of their health, such as skin health or mental health, care coordination among a variety of specialists is a necessity for caregivers. Websites, such as the Crohn's and Colitis Foundation, ImproveCareNow, and the Rome Foundation can be used to find and compare different providers that you require as part of your child's care team. Being a part of a support group may also be useful in this situation to identify and compare recommended providers. Your child's doctor may also refer you to a specialist. When comparing specialists, consider location and whether it will be manageable to travel to the specialist on a regular basis. You may consider asking your doctor for multiple referrals in order to compare cost, location, and quality. When piecing together your care team, case managers and nurse coordinators may be useful in helping you communicate information and records between providers.

Because certain medications to treat your child's Crohn's disease may cause side effects on other aspects of their health, such as skin health or mental health, care coordination among a variety of specialists is a necessity for caregivers.

Another alternative to an IBD Center is a Medical Home,³¹ a recently developed patient-centered model of care for IBD patients. In the Medical Home model, the patient's gastroenterologist is the principal care provider and collaborates with insurance companies and payers to refer the patient to other specialists. According to the National Center for Biotechnology Information (NCBI), the difference between an IBD center and a Medical Home is the following:

³¹Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5495046/>.

“The traditional IBD medical center is usually referred to as a center of excellence and is part of a large academic center. That model is built around a health care provider, for example the gastroenterologist, and relies on referrals of IBD patients to the provider via primary care physicians or other doctors. The physician is rated or paid based on relative value units (e.g., the number of office visits and procedures) in a fee-for-service equation. This traditional IBD model is mainly supported by the institution or hospital, whereby downstream revenue from IBD care by surgeons, pathologists, radiologists, and so on goes to the hospital, which then gives money to the center to hire additional staff and provide program development.

The medical-home model differs in that the center of the health care universe is not the health care provider, but the patient. This model tries to figure out how to provide care that is patient-centered. The gastroenterologist does not become the referral specialist; the gastroenterologist essentially becomes the principal care provider. The collaboration is not so much with the hospital or institution, but more with the insurance company or payer, which is referring patients in a population-based way to the medical home in addition to the primary care physician and other doctors.”

For more information on Medical Homes, check out the [Resources](#) section.

Help with Activities of Care

Our national study and listening sessions with caregivers indicated that many IBD caregivers provide help with preparing meals, care coordination, household management, and finances. Most IBD caregivers report scheduling and attending appointments; and talking with physicians, therapists, and nutritionists. Eight out of 10 IBD caregivers report providing or helping to find transportation (82 percent) and grocery or other shopping (80 percent). Roughly three in four IBD caregivers (73 percent) report doing household chores, and more than half (62 percent) assist with managing finances and filing for insurance.

Caregivers in our listening sessions indicated that keeping routines and personal best practices around these tasks is what helped them the most in feeling a sense of control. Consider keeping a calendar of your child's appointments, having a pill keeper and alarm to stay on track with your child's medications, having a food log to track what your child has eaten and drank in a day. Caregivers in our listening sessions also mentioned the importance of keeping track of medical records, as well as taking notes at doctor's appointments. Whatever you decide to do, make sure to involve your child in some capacity in these routines. This will help them prepare to take on more responsibility as they get older.



Consider keeping a calendar of your child's appointments, having a pill keeper and alarm to stay on track with your child's medications, having a food log to track what your child has eaten and drank in a day.

Medical/Nursing Tasks

Our national study found that IBD caregivers may also assist with medical/nursing tasks. The most commonly reported medical/nursing task was assistance with managing medication, with nearly three in four caregivers (73 percent) helping with pills or injections. Nearly a third of IBD caregivers (29 percent) assisted with wound care, and roughly one in five (18 percent) assisted with hospital equipment, such as suctioning tubes. Although other caregivers did support medical tasks beyond these (as described below), these tasks were the most common. Of caregivers who reported conducting medical/nursing tasks, only about one-third reported having received prior preparation or training. Some of these were complex medical/nursing tasks, such as ostomy bag maintenance.

Without doctors or clinicians checking up on caregivers' comfort handling medical/nursing tasks, caregivers may need to advocate for themselves to acquire the proper training and information to take these tasks on. It's also important to involve your child in whatever training or information you receive to perform medical/nursing tasks, since your child will one day have to take on this responsibility themselves.

Managing Transitions of Care

In their journey with Crohn's disease, your child may need to be transferred to the hospital for certain procedures. Transitions from hospital admissions to home care and vice versa can be strenuous on both the caregiver and care recipient. How this transition is handled can make all the difference in helping you and your child

feel more in control. Being fully aware of your choices as well as the challenges, opportunities, and resources is critical and can help to mediate the challenges you may face in your role as caregiver in this situation.

Discussions with healthcare professionals should start early: we suggest starting the discussion about plans for discharge at the time of admission. There are many terms related to what is known as 'discharge planning' and educating yourself is key to advocating for a successful transition for your care recipient. When a care recipient is admitted to the hospital, or spends time in the emergency department, some medical professionals may use terms such as continuity of care or care transitions. Both terms refer to the time and the process between preparing to leave a hospital setting and going home. This process should be person-centered and driven by outcomes related to a successful transition for your child. Armed with information and awareness, you can be sure to make this process a smoother transition.

The Agency for Healthcare Research and Quality (AHRQ) developed a discharge planning overview that provides a roadmap for successful transitions and continuity of care. The elements of a successful discharge planning process are outlined below. It is critical that you are: (1) involved; (2) included in the discussions; and, (3) educated. As the caregiver, you should expect and insist that the following occurs between you, the person you care for, and the discharge planning team:

- **Include:** You and the person you care for should be included as full partners in the discharge planning process.
- **Discuss:** You and the person you care for should discuss five key areas to prevent problems at home:
 - Describe what life at home will be like;
 - Review medications;
 - Highlight warning signs and problems;
 - Explain test results; and
 - Make follow-up appointments.
- **Educate:** You and the person you care for should learn about the condition, the discharge process, and next steps throughout the hospital stay.

For more help in this area, check out our [Resources](#) section at the end of the Guidebook.



The Centers for Medicare & Medicaid Services (CMS) suggests considering the following when preparing to leave the hospital:

- What's Ahead?
 - What services and programs are available?
 - Who can help?
- Your Care Recipient's Health
 - How can I help them? How can they help themselves?
 - Activities of daily living
 - Medications
- Recovery and Support
 - Support groups
 - Peer counseling
- Your Health
 - Education and training
 - Getting the help and support you need

Home Health Care Aide

Home health care aides provide help or respite during periods where the burden of tasks can be both physically and emotionally overwhelming for you as a caregiver. Home health care aides do not perform medical tasks or services that require a nurse, but they do provide aid that can help ease caregiver stress, which may allow caregivers to successfully and sustainably care for their children. Home health care services may include assisting in daily activities for the child, such as bathing, grooming, feeding, dressing, respite care for the caregiver, light housekeeping, and errand-running. Home health care services may be covered by private insurance or by Medicaid depending on state eligibility criteria.



The option to have your child participate in clinical research trials remains at your discretion as the caregiver.

Clinical Trials

As therapies are developed, they go through a process of being evaluated and approved by the FDA before they can be available to the public. This requires clinical trials to be conducted on new experimental therapies. Clinical trials may be an option for your child, particularly if other treatments do not work or there are no other treatments. Locating researchers and gaining access to appropriate clinical studies can require dedication and flexibility. Information on clinical studies conducted for IBD patients can be found at <https://www.crohnscolitisfoundation.org/clinical-trials-community/pediatric-clinical-trials>.

You may feel hesitant to enroll your child in clinical trials for therapies, particularly if you are part of an underserved community. Trust in the medical system has long been a barrier to research participation among communities of color.³² Despite national efforts led by the NIH and the FDA, research participation remains low for underrepresented groups designated by race, ethnicity, gender, socioeconomic status, and age. In addition, medical provider bias is a systemic problem that contributes to underserved patients not being asked to participate in research.

Lack of diversity in research participation can have serious consequences, including being unable to generalize study results to advance effective therapies, and preventing some populations from experiencing the benefits of research innovations. However, the option to have your child participate in clinical research trials remains at your discretion as the caregiver.

Mental Health Care

Access to mental health care for children can be challenging. Having Crohn's disease can amplify mental healthcare needs. Emotional exhaustion, anxiety, and stress have all been recognized in the Crohn's disease population.

It can be difficult to find pediatric mental health providers nearby and often families travel long distances or have to endure long waiting lists to get care. Insurance coverage and cost add to the challenge of getting care for a child. Patients and caregiver mental health concerns are sometimes not taken seriously or can be misdiagnosed. It is important that you discuss mental well-being concerns with a child's pediatrician or specialist and advocate for additional support when needed. You know your child best, trust your judgement. Be diligent and do not lose hope. These care challenges may feel overwhelming, but, there are tools and supports to help.

The National Alliance on Mental Illness (NAMI) is a leading voice on mental health. As a grassroots mental health organization aligned with over 600 local affiliates, NAMI works to educate, advocate, listen, and lead to improve the lives of Americans with mental illness and their loved ones.

How and When to Access Mental Health Care

The caregiver and patient's journey with Crohn's disease can be stressful and emotionally exhausting. It's important to find care for yourself and your child early on, and not wait for a crisis to occur. Upon diagnosis, you should consider adding a mental health provider to your child's care team. Ask your child's doctor for a referral to a clinical psychologist or mental health provider,

³²Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010). *More than Tuskegee: understanding mistrust about research participation*. *Journal of Health Care for the Poor and Underserved*, 21(3), 879.



Every child is different, and thus, every child will have different ways of coping with their Crohn's disease. There is no one-size-fits-all approach to coping with Crohn's,

especially one with an understanding of GI issues, such as a GI psychologist or social worker. Before sending your child to a mental health provider, make sure their services are covered within your insurance plan, as some might not be covered under your insurance plan. If that's the case, try checking out psychologists or other mental health practitioners with a slightly broader focus on health issues or chronic illness.

When sending your child to a mental health provider, it's important they know that if they don't "click" with that provider, your child doesn't have to stay with them. It's okay to "shop around" for different providers, as your child's comfort in utilizing mental health resources is a key priority. It's also important to make sure that your child's therapist or psychologist is communicating with their doctor, and is an active part of the entire care team.

Coping Strategies

Every child is different, and thus, every child will have different ways of coping with their Crohn's disease. There is no one-size-fits-all approach to coping with Crohn's, however, there are several resources out there with tips to help you and your child learn to live and thrive with Crohn's disease.

Some tips include:

- Celebrating the wins;
- Practicing gratitude for all the positive aspects of your child's life;
- Practicing relaxation techniques, and incorporating meditation and mindfulness;
- Scheduling time to rest and using activity pacing strategies; and
- Planning something fun to look forward to.

For more resources on coping with IBD, check out the [Resources](#) section at the end of this Guidebook.

Managing Health Care Records

As previously mentioned, managing and keeping track of your child's healthcare records is a key aspect of understanding your child's health progress and communicating with the rest of the care team. If your child were to ever change doctors or add a specialist to the care team, being able to share medical records and documents with that new provider is important to make sure they have an understanding of your child's medical history. In our listening sessions, caregivers mentioned keeping and organizing medical records, visitor summaries, and notes from doctor's appointments. They also mentioned making copies of all important documents to ensure that nothing gets lost. Passing on these processes to your child or adolescent and teaching them the system is important in empowering them to take charge of their own disease.

Access to your child's medical records changes when they turn 18. Unless you sign a release form, you won't have ease of access to their healthcare records. It's important to discuss this with your adolescent, as having access to their medical records could be beneficial to them in anticipation that if they were to get sick again, the role of care coordinator would once again fall on the caregiver, especially if the patient still lives at home.

A Medical Power of Attorney form allows a parent to be a health care proxy for their child if the child is over the age of 18 and unable to make medical decisions on their own. Without this form, health providers are legally prohibited from sharing diagnoses, medical information, test results, etc. with parents, which can be very tough for parents who still consider themselves partners in their child's health care. This form is particularly important for Crohn's patients who are transitioning into young adulthood and/or going to college, but who might not be ready to start making decisions and keep track of medical records on their own, especially during a flare-up. This free form can be found online for each state and does not require an attorney to notarize it.



EMPOWERING YOUR CHILD TO MANAGE THEIR CROHN'S DISEASE

About the Author

Lilly Stairs is a three times autoimmune disease patient and advocate living with Crohn's disease, psoriatic arthritis, and psoriasis. From the moment she was in the hospital bed at age 19, she knew that she was destined to become a patient advocate and has dedicated the past ten years of her life to serving the autoimmune patient community.

Lilly is the Founder and Principal at Patient Authentic, where she helps healthcare organizations build programs that educate and empower patients. She regularly shares her experience and expertise via speaking engagements from conferences to Capitol Hill, serves as a Board Member for the American Autoimmune Related Diseases Association (AARDA), and is a Lead Patient Advisor to several major pharmaceutical and health tech companies.

In this section, Lilly walks through practical advice for empowering your child to manage their Crohn's disease and weaves in her personal experience being diagnosed with IBD as a young adult.

Introduction

Every child and teen goes through phases of growth and a yearning for independence. Knowing when and how to let your child “fly” can be difficult to navigate. Add managing a serious chronic condition to that list, and it can feel downright overwhelming.

In this section, we'll tackle strategies you can implement to empower your child to help manage their IBD. We'll cover everything from care transitions to creating active opportunities for your child to work alongside you in managing their care.



TALKING TO YOUR CHILD ABOUT IBD³³

Depending on age and circumstances surrounding your child's diagnosis, it may fall to you to disclose the diagnosis to your child if it is not delivered by a medical professional. Even if you are not responsible for delivering the diagnosis, you will undoubtedly be engaging in many conversations about the way Crohn's impacts your child's day-to-day life, as well as their treatment and care plan.

Ultimately, you know your child best, so when and how you deliver information should be based on how you think it will be best received by your child.

To provide some support, we've compiled a series of guidelines to consider when discussing IBD with your child.

Find a Safe Space

Find a safe, private space to chat with plenty of time for discussion without constraints.

Use Clear Language

Use clear and simple language when explaining diagnosis, treatment, or another aspect of living with IBD.



For example, when explaining a diagnosis, consider discussing the following:

- The symptoms they have been experiencing are because of something called Crohn's disease;
- Crohn's disease impacts the digestive system;
- How/where the Crohn's is manifesting in their body (consider using visual aids);

If they are at an age where they can grasp the concept, explain that Crohn's is an autoimmune disease. When an immune system is functioning normally, it attacks germs and viruses. Crohn's disease occurs because the body is mistakenly attacking healthy cells, and this results in the symptoms they are experiencing.

³³Crohn's & Colitis UK (2018, March). *Talking to My Child About My IBD*. Retrieved from <https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/talking-to-my-child-about-my-ibd>.

Use Visual Aids

Some children or teens may be visual learners and might respond well to diagrams or video. See the Crohn's and Colitis Foundation for visual resources for kids.

Be Honest and Encouraging

Be realistic about challenges they may face because of the disease, but that with proper treatment, many children go on to live a "normal" life.

Pause for Questions

Don't forget to give your child space to ask questions. Share bits of information, then make a concentrated effort to pause so that they may react.

Deliver Information in "Doses" (as needed)

Don't feel as if you have to communicate everything your child will ever need to know at once. Read their reaction and know that you can always have the conversation in "doses" over time to make the diagnosis and treatment plan feel more palatable.

Engage in Shared Decision-Making

When discussing a care and treatment plan, open up the opportunity for your child to take part in the decision-making process if there are options available.

Note: Shared-decision making is defined as a "communication process by which patients and clinicians work together to make optimal health care decisions that align with what matters most to patients."

Share Resources

Share trusted resources with your child that they can review at their own pace to learn more and to help inform any shared decision-making they engage in.

Encourage an Ongoing Dialogue

Encourage your child to keep asking questions and sharing their thoughts and feelings. Let them know that they are not alone; you are in this together and you will do whatever you can to support them.



A NOTE FROM THE AUTHOR

When I was first diagnosed with Crohn's disease, I was extremely sick. My body was in a heightened state of inflammation. I had total body joint pain and lost thirty pounds while in the hospital from bleeding ulcers in my small intestine. I was terrified and scared of what my future would hold. After being released from the hospital, I began a long journey to find a treatment that worked for me. During this time, my mother—my primary caregiver—and I often had discussions about my diagnosis. She always reminded me that "everyone has something". Every person eventually faces an adversity they must overcome in their life. My autoimmune diagnoses are mine. This framing was instrumental in helping me cope. Now, instead of viewing my autoimmune diseases as a weakness, I view them as a strength. Having been in remission for several years, I often reflect on how strong I am for what I have endured. When I encounter parents to children living with IBD, my advice to them is to remind their child that everyone has a battle they must fight in life and that their experience living with IBD will make them stronger.



MANAGING CARE TRANSITIONS

Assent to Consent to Care Partner

Framing your child's care from assent to consent to care partner is a strong foundation for understanding the way their involvement in their care naturally transitions over time.

Assent:

In the context of healthcare, assent is used when a child is under the age of 18 and unable to legally give "consent". When a child assents to something, it means they understand and have given their approval.

When the child is old enough to comprehend what is happening in their care, it is important for the care team to explain the proposed treatment plan and strive to obtain the child's approval or assent to move forward. Ultimately, however, consent must be given by the child's legal parent or guardian if they are under age 18.

Consent:

At the age of 18 in the United States, persons are legally allowed to give their consent when it comes to healthcare matters without the approval of a parent or guardian. At this stage, children may still consult their parent or guardian, but, they will ultimately have the right to control their treatment plan.

Care Partner:

When a child turns 18, or in some cases, even before the age of 18, a parent or guardian transitions into the role of “care partner” instead of sole caregiver. This means that the child is taking an active role in their care and decision-making process while still working closely with their parent or guardian to manage their care. That being said, even when parents transition from caregiver to care partner, there are likely still times where they resume their caregiver role, especially during a flare up.

Note: *When IBD symptoms are active, it is often referred to as a “flare up.”*

Pediatric to Adult Care Systems

There will come a point in time when your child needs to transition from pediatric care to adult care. We've compiled a list of three important tips from parents who helped their child make the transition:

- **Ask for recommendations** from your pediatric gastroenterologist, pediatrician, or fellow parents in the same boat.
- **Stay within one health system** when possible. Centralizing care by having a child's primary care provider (PCP) and specialists within one system makes care coordination much easier. All specialists can access the same portal to view notes, lab results, etc. It's important to note that in some cases, specialists may refuse to coordinate care outside of their network.
- **Discuss medical record access** ahead of your child turning 18. *(More on this in the next section!)*

Accessing Medical Records as a Caregiver

Once your child turns 18, you can no longer access their medical information or coordinate their care without consent. Consent typically involves your child signing HIPAA release forms.

Unfortunately there is no form that universally applies throughout our healthcare system. Your child will need to give consent for you to access their information with each health system, insurance provider, and any other entity they interface with that handles medical records.

It is important to discuss access to medical records with your child—ideally before they turn 18—to help ensure a smooth care transition. Even if they already are or are intending to become independent in their care, it's generally an easier transition if parents or guardians have some level of access to children's medical records, especially if there is an emergency or your child goes into a flare that renders them unable to coordinate their own care.

**EMPOWERING YOUR CHILD TO BE SAFE AND INDEPENDENT (AT EVERY AGE!)**

Helping your child feel empowered and giving them an opportunity to take an active role in their disease management helps establish a strong foundation for the moment in time when they transition from pediatric to adult care and become independent.

Involving your child in their care is an empowering exercise and there are many ways by which to introduce this concept. We've compiled a list to help get you started and get the juices flowing for ways in which you can adapt this to fit your child's needs.

Engage in Shared Decision-Making

Shared decision-making is a great way for your child's voice to be heard. Not only can you involve your child in shared decision-making when it comes to treatment decisions, but also when it comes to their care. When they are able, let your child voice what they feel they can and can't do. Generally speaking, children of any age can be involved in their care to varying degrees. As their caregiver, keep a close eye to monitor their stress levels and ensure they don't have too much on their plate.

Create Opportunities for Active Listening & Learning

Consider the responsibilities you have taken on to help manage your child's IBD. Where are opportunities for your child to actively listen and learn from how you complete these tasks?

Care Coordination

While chatting with one mother about her child's IBD, she said she saves all of her calls to her health insurance company for car rides where she and her child are traveling together to the child's infusion. She puts the insurance company on speaker phone, and encourages her child to listen while she navigates so that they can begin to learn what is involved and how they should approach these conversations.

Preparing for Appointments

Talk with your child ahead of their doctor appointments. Ask them to develop a list of questions they would like answered and, while in the appointment, let your child take the lead in reporting on how they are feeling and asking questions.

Managing Dietary Restrictions

If your child has dietary restrictions, involve them in grocery shopping and meal preparation. Show them how you read labels and what you look for while shopping. Make them your sous-chef in the kitchen.

Active Role in Treatment Management

Adhering to prescribed treatment is critical to successful management of IBD. Finding ways to involve your child in this process is important. If they take pills, assign them the responsibility of filling a pill box each week or have them set a personal reminder to take their medication. If they get an infusion at the hospital, encourage them to make the appointment with you and/or add it to their personal calendar. If you inject medication on their behalf, encourage them to get everything set up for the injection, including cleaning the area on the skin where the injection will be administered.

Even toddlers can get involved in this process! As you develop routines, explain to your toddler why these processes are in place to reinforce their importance. For example, set alarms that go off when the toddler needs to take their medication—they will begin to understand what that sound means and why it is important.

It's also important for your child to know to be honest with you if they have not been following the prescribed treatment plan. Your child should know that it is critical to be honest about this and find a way to get back on track together and with your child's GI doctor.

Share Resources

As you come across resources that are helpful to you in learning about IBD or managing your child's care, share them with your child so that they can learn along with you.



A Note on Managing Physician Pushback

When conducting listening sessions for the development of this guidebook, participants commented that some physicians might not always feel comfortable when parents are present during a child's appointment. It's important to reiterate that you are a part of the care team, so as long as your child needs and wants you to be there for support, you will be there. As the primary caregiver, you have a wealth of knowledge living with the patient every day. It's important for your doctor to understand that so they can leverage your knowledge to improve the child's care outcomes.

Adhering to prescribed treatment is critical to successful management of IBD. Finding ways to involve your child in this process is important.



FOOD & NUTRITION

Teaching Your Child Nutrition Strategies

There is no one diet for IBD that is widely recommended. Every child is different and will likely have foods that can trigger IBD symptoms or flares.

Working with a nutritionist to identify and remove those foods from a child's diet is important in care management. Exposing your child to how you effectively do this will be essential to their safety when you are not present and, eventually, when they take over managing their own care.

Go Grocery Shopping Together

Bring your child grocery shopping with you. If they have specific allergens or restrictions, show them how you read labels. Encourage them to start reading the labels and double-checking ingredients. The Food Allergy Foundation has a handy checklist detailing how to read a food label. You can access it here: <https://www.foodallergy.org/resources/how-read-food-label>

Meal Prep Together

Research meal ideas together to get your child excited about what's on the menu. Invite them to cook with you in the kitchen!

Always Be Prepared!

Teach your child to always be prepared with a snack on hand they know is safe to eat so they don't end up going hungry if they are in a scenario where they do not have control over food preparation.

Going Out for Meals

Research restaurants with your child ahead of time that are able to accommodate their dietary needs. Encourage your child to observe and listen when you interface with the restaurant staff and, as they are comfortable, encourage them to speak up about restrictions or allergies when they order.

Healthy Habits

Your child may not have a specific allergy or restriction, but fostering healthy nutrition habits is important for overall health and keeping IBD in check. Explain to your child why it is important to eat healthy, not only for general well-being, but also to help manage their IBD. Take time to explain what foods are considered healthy and make an effort to integrate those into your child's diet so that they begin to develop healthy eating habits.



Every child is different and will likely have foods that can trigger IBD symptoms or flares.

Common Issues

Sneaking Food

Sometimes children or adolescents will sneak food, especially when they are away from home and out with friends. This often stems from feelings of "missing out" in a social scenario or from missing the taste of certain foods. To help avoid these scenarios, be prepared with alternatives. If a trigger food is a known favorite, find an alternative that is made with different ingredients. For example, if gluten is a trigger, find pre-made gluten-free pizza, cookies, etc. at the grocery store or recipes to make on your own. Websites like Pinterest allow you to search thousands of recipes that accommodate most dietary restrictions. Certain restaurants also tend to be more diet restriction-friendly than others; map those out to share with your child and encourage them to go to those restaurants with their friends.

Appetite Changes & Weight Gain

Prednisone, a treatment for IBD that is becoming less common, can often be the cause of appetite changes and weight gain. There are a few tactics to help manage these side effects, including:³⁴

- Reducing salt intake;
- Avoiding processed foods;
- Instead of eating three meals a day, eating smaller, more frequent meals;
- Drinking water;
- Exercising for 30 minutes every day.

Weight Loss & Malnutrition

According to the Crohn's and Colitis Foundation, "Crohn's disease and ulcerative colitis can impact your body's ability to properly digest food and absorb nutrients, which may lead to serious vitamin deficiencies and malnutrition."³⁵

If your child experiences malnutrition from their Crohn's disease, it is important to work closely with your healthcare team to identify a plan to ensure your child maintains their nutrition. When your child is flaring and is struggling to eat food, nutritional supplement shakes can be helpful. In more severe cases, your physician can prescribe a feeding tube or prescription medical therapy.

Access to IBD friendly food

Travel

Prior to going on a trip, research restaurants and grocery stores ahead of time. If your child has a very strict diet or allergies, it is likely important to find accommodations where you have access to a kitchen. Pack some snacks from home and have a few on hand wherever you go.

Social Outings/Events

Send your child with a few snacks to have on hand if they are headed to a party or event. You can also call a restaurant or fellow parent/teacher/guardian hosting an event ahead of time to discuss what is safe for your child to eat. Be sure to review this with your child ahead of time.

Helpful resource

The Food Allergy Foundation is a great resource for navigating food allergies and dietary restrictions and how to prepare for scenarios like travel, eating out at restaurants, college etc. Visit <https://www.foodallergy.org/> for support.



Food as comfort / Food as control

From a Licensed Clinical Social Worker, Stephanie Brenner:

As a clinical social worker who treats many Crohn's patients, it is important to normalize that the patient's relationship with food will be altered because of this disease. This can look like bingeing, restricting, using food for comfort, viewing food as a weapon, extreme weight loss, or extreme weight gain. It is important for the physician to screen the patient for disordered eating, assess the patient regularly for this, and talk about what disordered eating behaviors may look like. Because food is so closely related to pain or disease symptoms, many patients develop food phobias or start to avoid or restrict various foods. Ask questions about diet to your physician and be wary of any restrictive diets without hearing the evidence for it and getting support from a registered dietician. If you notice your child struggling around food choices or weight issues, it is best to have a multidisciplinary team approach with a GI mental health provider as well as a GI specific dietician for support.

If your child experiences malnutrition from their Crohn's disease, it is important to work closely with your healthcare team to identify a plan to ensure your child maintains their nutrition.

³⁴Cincinnati Children's Blog (2016, July 8). Retrieved from <https://blog.cincinnatichildrens.org/rare-and-complex-conditions/ibd-tips-for-managing-steroid-side-effects/>. ³⁵The Crohn's and Colitis Foundation. Retrieved from <https://www.crohnscolitisfoundation.org/diet-and-nutrition/malnutrition-and-ibd>.



TEACHING YOUR CHILD SELF-CARE STRATEGIES

Developing self-care strategies is important for any child, but especially for children and adolescents living with IBD. With stress being a known trigger of flares, teaching your children tactics they can use and reinforcing those habits will set them up for success in managing their disease now and in the future.

Self-care comes in many forms and what works best for one person might not resonate as well with someone else.

Here is a list of ideas to get you started. Pick one or two activities to engage in daily or a few times a week with your child. Make it a part of their routine and vocalize that this is “self-care” time to de-stress and relax.

- Meditation
- Exercise/Yoga
- Reading
- Spend time in nature
- Creative writing
- Gratitude journal

A NOTE FROM THE AUTHOR

In addition to practicing self-care strategies at home, consider enrolling your child in therapy. There are now many therapists who specialize in treating patients living with a physical chronic illness. Teaching your child to prioritize their mental health just as they do their physical health is important, and therapy can be a great way to normalize this practice from a young age. Therapists can also teach your child coping mechanisms for managing flares, social life, and other experiences that are impacted by their IBD. For more information, please see the section on [Finding a Mental Health Provider](#).



EMPOWERING YOUR CHILD TO HAVE MEANINGFUL RELATIONSHIPS

Friends

Navigating friendships with a chronic illness can be tough. Especially with a condition like IBD that is largely invisible. It can be difficult for your child's peers to understand IBD.

The decision to disclose an IBD diagnosis to friends is dependent on your child's comfort level. Open a dialogue with them to discuss how they would like to handle the situation. If they are fearful their friends will treat them differently or no longer want to be their friend, remind them that a true friend will support them.

How much your child discloses is also based on their comfort level. However, explaining how IBD impacts them personally can be helpful for friends to understand so that they know how to best support your child and empathize.

Encouraging your child to maintain friendships is important. It can also be a valuable experience for your child to welcome new friends into their life who have IBD. To help your child connect with other people living with IBD, consider sending them to Camp Oasis. Camp Oasis is a summer camp run by the Crohn's and Colitis Foundation and brings together children and adolescents living with IBD so that they can form friendships with peers who understand what they are going through. (The Foundation offers scholarships for those who do not have the financial resources to pay for camp).

Girls With Guts is another in-person option that offers a retreat for women (including young adults) living with IBD.

Online forums like Inspire, Facebook groups, as well as following social media hashtags (#IBD, #Crohns) can help teens and young adults connect with fellow IBD friends.

Social Media Disclosure

Just as it is your child's decision to disclose their IBD to friends, it is also up to them if they would like to disclose their diagnosis more broadly on social media. It's important to note that a younger child might need more guidance from their parents or guardian on whether or not to share personal medical details.

Sharing on social media can be a great way to help peers understand what you are going through and also an empowering tool to raise awareness about living with IBD.



A NOTE FROM THE AUTHOR

In the chronic illness world, we often talk about how a diagnosis reveals who your true friends are. There will likely be friends who are unable to be there to support you, either because they can't emotionally handle it or they don't want to. This can be a difficult concept to come to terms with at any age, but especially for children and adolescents. I often think of my chronic illnesses as blessings in disguise, and learning who your true friends are is just that. As Crohn's advocate Kathleen Nicholls shares in her article on the Mighty, "Ridding your life of toxic people or just dead wood in your friendships makes more room for the good ones to get in. It can be hard enough to make time for your loved ones, so don't waste valuable time on those who don't deserve it. That should really be a general rule for life, illness or not. Making allowances for the way your illness affects those around you is crucial."³⁶

Romantic Relationships

Talking to a Romantic Partner About IBD

There is no set rule for when it is appropriate to disclose an IBD diagnosis to a romantic partner or someone you are dating. If your child comes to you to discuss this topic, assure them that they can control when they want to share and how much they want to disclose. Most people might not want to share this information on the first date, but, after they've had time to get to know the person and potentially see it going somewhere, they may feel more comfortable to broach the subject.³⁷

There's no pressure to divulge everything, but sharing high level details is generally a good starting point. Just as with friends, your child may encounter prospective partners who are not equipped to handle chronic illness. It's never easy to deal with this, but it just means they learn sooner rather than later that that person isn't right for them.

That being said, there are millions of people living with chronic illnesses like IBD who have happy, loving, successful relationships, and it is important to remind your child of this and share stories of IBD patients who have found love.

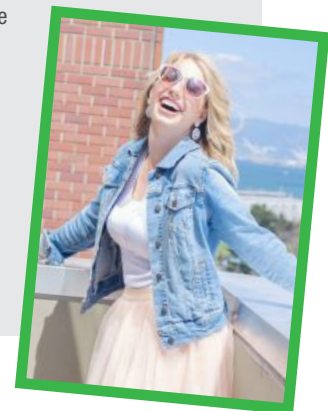
Sexual Health

As your child reaches their teen years, it is especially important for them to have the ability to talk with their gastroenterologist without a parent or guardian in the room to ask questions they may not feel comfortable asking in front of you. This might include questions such as being intimate with IBD.

The Crohn's and Colitis Foundation's National Council of College Leaders has some great resources on sexual health and IBD if you want to support your child, but are unsure how or what to say. A strong starting point is this webinar featuring college students on the topic of being intimate with IBD: <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/social-life>.

A NOTE FROM THE AUTHOR

I've dated and had a few serious relationships since I was diagnosed with IBD. The majority of my partners have been understanding and dating has been a very positive experience for me overall. I did have one partner who disclosed he was afraid of my autoimmune diseases and this was initially difficult for me to accept. I wrote a piece for the Crohn's and Colitis Foundation on the topic.³⁸ My main takeaway is to always remember that **everyone has something**. No one escapes life without facing hardship. My autoimmune diseases have made me a stronger person, and I like to think that makes me a special partner to whomever I am with as I am well equipped to help them navigate hardships they experience.



³⁶The Mighty (2015, December 28). *When Your Chronic Illness Reveals Who Your True Friends Are*. Retrieved from <https://themighty.com/2015/12/when-your-chronic-illness-reveals-who-your-true-friends-are/>. ³⁷<https://www.healthline.com/health/crohns-disease/dating-tips#Dealing-with-symptoms-while-dating> ³⁸Crohn's and Colitis Foundation. *Lilly's Story*. Retrieved from https://online.crohnscolitisfoundation.org/site/SPageNavigator/awareness_hero_lilly.html?jsessionid=00000000.app330a?NONCE_TOKEN=F48B2DEA8A23362E89F8C4107BC025FC&hss_channel=fbp-101393913279829&utm_medium=social&utm_content=80652198&utm_source=facebook&utm_campaign=Awareness%2520Week%25202018



MANAGING DIFFICULT CONVERSATIONS WITH YOUR CHILD

Treatment & Surgery

The principles covered in the [Talking to Your Child About IBD](#) section certainly apply to discussions surrounding treatment and surgery, as well.

Reinforce the Importance of Treatment

As your child's primary caretaker, it is of critical importance to reinforce how essential it is for your child to take their medicine the way it was prescribed. Explain to them that even if they are feeling better, they can't stop taking the medicine or they risk "getting sick" again or going into a flare. Instilling good habits when it comes to treatment adherence when children are young helps set them up for success in managing their condition in the long run.

When it comes to treatment, it's also important to be realistic about what's possible and work together to find the right regiment. For example, in one of our listening sessions, a parent mentioned that an option to treat her son's IBD was through a liquid diet. He admitted that he wouldn't be able to stick to that, so they explored more realistic options that accommodated his lifestyle.

Addressing Fear of Needles

While not all IBD treatments involve needles, many options do. For children and teens who are needle-phobic, it might be helpful to call on a psychologist or therapist who can help give your child tactics to manage their fear.

Surgery

Surgery is understandably a scary concept for most people. If your child requires surgery to manage their IBD, work with your gastroenterologist and surgeon to help your child understand what the surgery entails with a focus on the intended goal—that the doctors are doing surgery so that your child can start to feel better and get their condition under control.

Ostomy

More so than other surgeries, the decision to get an ostomy not only has a physical impact, but a mental one, as well. Providing your child with support and resources from fellow IBD patients who live with an ostomy is important. A great starting point is ImproveCareNow's Patient Advisory Council's toolkit, "For Pediatric Ostomates, from Pediatric Ostomates" that has helpful stories and tips for "gutsy living" with an ostomate.

A NOTE FROM THE AUTHOR

Growing up, I had major needle-phobia—so much so that when a nurse was about to administer a flu shot at my pediatrician's office, I jumped off the table and ran out...at an age well beyond when that behavior was acceptable. After my Crohn's diagnosis, needles became my weekly reality. I adapted. I overcame my fear of needles, and now, I inject myself with a pre-filled syringe. I have drawn so much strength from this experience and it just serves as another reminder of the ways in which chronic illness has made me a stronger person.

"Teen Talks"

While in the previous section we noted the importance of giving your adolescent space to ask their physician questions they might not be comfortable answering in front of you, if your child isn't asking, it may fall to you to ask some of these questions.

In the listening sessions conducted to help shape this guidebook, we asked parents how they handle these difficult questions and conversations. A few parents encouraged asking the gastroenterologist about alcohol, drugs, and cigarette-smoking interaction in front of your child to ensure they hear and understand the consequences, and also to normalize the concept of talking about these sensitive topics with a physician.

While every parent's approach is different, another parent said she communicates to her child that their safety is important above all else. If your child finds themselves in a scenario where they have been drinking or smoking and fear their health is at risk, they shouldn't hesitate to call immediately—their health and safety supersedes them doing something wrong.

In Conclusion: Equipping Your Child To Advocate For Themselves

Throughout this section, we've covered ways that you can empower your child to manage their IBD. All of these tools and resources will ultimately equip your child to advocate for themselves now and in the future.

Above all else, consistently identifying ways your child can get involved in actively managing their care and leading by example are two of the most important ways you can set your child up for success in managing their care as they become independent.

Remember that you know your child best, and while we've researched and collected best practices from fellow caregivers, we recognize that every patient and caregiver journey is different just as every child is different. Trust your gut and use these tools to help guide you and your child as you navigate IBD.

A photograph of a woman with dark hair, smiling broadly with her eyes closed. A young boy with dark hair, wearing a green polo shirt, is leaning over her and kissing her forehead. The background is a soft-focus green field. A green diagonal line runs from the top right towards the bottom left, separating the image from the text below.

CARING FOR YOURSELF AND FOR YOUR FAMILY

Contributors to this section include: Mousumi Bose, Assistant Professor, Nutrition and Food Studies, Montclair State University; and Kimberly Haugstad, CEO, ACTION Partners, LLP; Co-founder, Upequity; Theresa J. Smith, AS, LPN, CCRC, Advance Directives Research Project Coordinator, Department of Humanities, Pennsylvania State College of Medicine; Field Nurse, Bayada Pediatrics.



FAMILY RELATIONSHIPS

Managing effective relationships within families can be challenging when caring for a child or adolescent with Crohn's disease. However, strong relationships with immediate and extended family can be a valuable tool in managing care. Family members, including partners and other children, can play roles in providing care to your child to ease the burden of the primary caregiver. This support may allow for caregivers to fulfill tasks outside of caregiving, such as employment. Family members can also provide emotional support to you.

To successfully achieve family support, it may be useful to clearly address and define roles that family members will play in providing support and sharing the responsibility of care management for the child. These conversations may be facilitated through family therapy and/or a social worker.

Marriage/Partnerships

Research suggests that parents may differ in the way they understand their child's disease, and that their lives might be impacted by the disease differently.⁴⁰ Every relationship suffers from periods of stress, but, there is additional stress when being the caregiver to a child with Crohn's disease. These may be financial stressors or stress associated with little free time or exhaustion due to caregiving responsibilities. Gender roles may also define who takes on more caregiving responsibility, increasing stress in a relationship. Without addressing them, these stressors can contribute additional strain on, or even the dissolution of a marriage or relationship.

Patience and reminders that emotional experiences related to caregiving can manifest in different ways can help communication across partners. Try to secure regular "alone" time together as partners. Take family and friends up on their offers of help and schedule time "off" for yourselves. Keeping up communication is very important and, if helpful, meet with a counselor to facilitate that communication, as well as to get tips to balance caregiving responsibilities. In the instances of co-parenting after a divorce, communication of roles and expectations is key so that the child's medical care is prioritized no matter which location they are in.



Other Children/Siblings

Siblings of children with Crohn's disease are often exposed to unique experiences distinct from other children, which may have positive or negative impacts on their well-being.⁴¹ While many have described increased empathy, cooperativity, and appreciation as a result of their experience, siblings of children with chronic illness are more likely to suffer from depression, anxiety, or other negative psychological outcomes.⁴² These siblings may resent how much of their parents' time and energy is taken up by their sibling with a chronic condition. They may be fearful of their and their family's future, or feel overwhelmed by the responsibility or obligations they have for their sibling's health and wellbeing.⁴³ Moreover, siblings may feel that they cannot express these feelings with their parents given their own burden of responsibility related to caregiving.

While it may seem like you should focus all of your energies on your child with Crohn's disease, it is important to provide siblings with their time and support, as well. These siblings are going through this experience alongside you. You can share information with them on a level they can understand. Age-appropriate literature about their sibling's diagnosis may be helpful. You can ask your child's GI or pediatrician for some recommendations, and we've included a couple of options in the [Resources](#) section.

Research shows that sibling support improves patient outcomes for children dealing with IBD.⁴⁴ The Crohn's and Colitis Foundation offers a helpful tool for family-based intervention to support both the patient with Crohn's and their siblings, with coping strategies for both the patient and rest of the family (see [Resources](#) section).

⁴⁰Cardinali, P., Migliorini, L. & Rania, N. (2019). The caregiving experiences of fathers and mothers of children with rare diseases in Italy: Challenges and social support perceptions. *Frontiers in Psychology*. Doi: 10.3389/fpsyg.2019.01780. ⁴¹Fleary, S. A., & Heffer, R. W. (2013). Impact of growing up with a chronically ill sibling on well siblings' late adolescent functioning. *ISRN family medicine*, 2013. ⁴²Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: A meta-analysis. *Journal of pediatric psychology*, 27(8), 699-710. ⁴³Ibid. ⁴⁴https://journals.lww.com/jpgn/fulltext/2005/10000/SIBLING_SUPPORT_IN_PEDIATRIC_INFLAMMATORY_BOWEL.179.aspx

Helping to create a balance among your children through chores and responsibilities can help to prevent resentment. It is also important to have family activities that do not revolve only around the needs of one child. To prevent siblings from feeling lonely, work in periods of one-on-one time and encourage activities with their friends or look for sibling support groups, such as Sibshops, www.siblingsupport.org, which contains workshops for siblings of children with special needs.



EXTENDED FAMILY, FRIENDS, AND OTHER SOCIAL INTERACTIONS

In our focus group discussions, many caregivers felt as if they could not be honest with friends or family members outside of their immediate family about their situation. One caregiver described her family members refusing to believe that she and her daughter with Crohn's disease were lying about the severity of her daughter's condition and symptoms. The discomfort associated with being open and honest about the nature of their family's situation often resulted in feelings of isolation in the caregivers. Additionally, although many friends and extended family wish to be helpful to their friends who are caregivers to children with Crohn's disease, they may not know how to effectively support caregivers in their journey.

Community Support

The community surrounding a caregiver for an individual with Crohn's disease is crucial to addressing caregiver needs and supporting the overall quality of life in the family. Community resources can be local or remote and can offer support through both informational and logistical guidance as well as emotional support.

Although it may seem initially challenging, consider asking trustworthy friends and family members for help, being specific on how you can be best supported. If possible, explain to them the isolation, exhaustion, stress, grief, or other emotions you might be experiencing. Being open, honest, and clear about what your needs are may provide guidance and directions to friends and family who feel otherwise helpless. Depending on the nature of the

relationship, friends and family within your network may serve as an effective support system for both emotional needs and for activities to ease the burden of everyday tasks for the caregiver, which may ultimately improve your own wellbeing as a caregiver.

For caregivers in certain cultures, it may be more difficult to talk about strain related to caregiving, since caregiving may be viewed as a role that one is expected to take on for sick or aging family members. In other cultures, there may be a negative stigma attached to caregiving, leading caregivers to keep feelings and complex emotions to themselves. Research shows that caregiving is stressful for caregivers of various backgrounds,⁴⁵ so no matter what culture, ethnicity, or religion you belong to, it's important to care for yourself. Ultimately, caring for yourself will help you be a better caregiver for your child or adolescent with Crohn's.

In our support groups and in our 2019 research study, caregivers of individuals with IBD reported managing complex feelings related to their child's Crohn's disease. Complex feelings described included:

- Grief for what their care recipient's life could have been like without IBD;
- Guilt that they contributed to their child's Crohn's diagnosis or made a wrong decision in terms of treatment;
- Frustration and anger at the healthcare and insurance system;
- Worry over when their child's next flare-up would occur or about what challenges their child may encounter later in life;
- Lack of control over the well-being of their child.

Many times, parents may report more anxiety than the child or adolescent, which may fuel anxiety in the child with Crohn's. Accessing mental health resources, as well as other resources to feel more in control, can reduce your anxiety as a caregiver, and help your child deal with any complex feelings, as well. Mental health resources include online and in-person support groups, therapy, social media forums, and getting involved in activities with the Crohn's community. Everyone is different and has different ways of coping with complex feelings. Explore the resources available to you and take time to consider what helps you feel more in control of your feelings and of your and your child's life.

Both umbrella advocacy organizations as well as disease-specific organizations (See [Resources](#) section) may provide resources for community support and respite for caregivers and the immediate family; the following table describes additional programs and organizations that can be beneficial to families affected by Crohn's disease.

⁴⁵<https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf> "The drop-off in caregiver self-rated health since 2015 is happening across most subgroups of caregivers. Caregivers report significantly worse health across all hours of care and ages of recipients; among both low- and high-income caregivers; among all marital statuses; and among both those who had a choice and those who had no choice in providing care," (p. 48)

CROHN'S AND COLITIS FOUNDATION

<https://www.crohnscolitisfoundation.org/>

The Crohn's and Colitis Foundation provides a range of resources to patients of all ages dealing with IBD, as well as their families. Resource topics range from help with social life, information about the disease, and care coordination. You can join a local chapter to get more involved with the community. The Crohn's and Colitis Foundation also established Camp Oasis, a summer camp exclusively for children with IBD to enrich their lives by providing a safe and supportive camp community.

IMPROVECARENOW

<https://www.improvecarenow.org/>

A collaborative chronic care network enabling patients, families, clinicians, and researchers to work together in a learning healthcare system to accelerate innovation, discovery, and the application of new knowledge in IBD.

GIKIDS

<https://gikids.org/about/>

GIKIDS is the patient outreach and education effort of NASPGHAN – the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition – an organization of more than 2,600 pediatric gastroenterologists, predominantly in 46 states, the District of Columbia, Puerto Rico, Mexico and eight provinces in Canada.

CENTER FOR PARENT INFORMATION AND RESOURCES

www.parentcenterhub.org

Parent Training and Information Centers (PTI) and Community Parent Resource Centers (CPRC) are state-based centers that provide direct services for children and youth with disabilities, families, professionals, and other organizations that support them. The organization helps parents participate effectively in their children's education and development, partnering with professionals and policy makers to improve outcomes for all children with disabilities.

COURAGEOUS PARENTS NETWORK

www.courageousparentsnetwork.org

Created to provide support for those caring for children with serious illness, this organization delivers programs and education to families as well as resources to providers delivering family-centered care. The goal is that families have confidence in their ability to be the best caregivers possible. Information and tools that address caregiver psychological and emotional issues and enable informed decision-making in healthcare is provided through videos, podcasts, discussion forums, and guides. Resources include working with the medical team, making difficult decisions, caring for siblings, and tending a marriage.

EASTER SEALS

www.easterseals.com

Provides state programs including early intervention, inclusive child care, medical rehabilitation and autism services for young children and their families, mental health programs, assistive technology, camp and recreation, and caregiving support, including respite.

DAVID'S REFUGE

www.davidsrefuge.org/about-us

A faith-based organization located in upstate New York that provides respite, resources, and support to parents and caregivers of children with special needs. Additionally, they offer virtual support and resources on health and wellness, as well as spirituality.

FAMILY VOICES

www.familyvoices.org

A national network of families and friends of children and youth with special health care needs and disabilities. The organization promotes partnership with families—including those of cultural, linguistic, and geographic diversity. Offers training and shares best practices and resources on family engagement and advocacy.

PARENT TO PARENT USA NETWORK

www.p2pusa.org/parents

Programs are state-based programs that offer parent-to-parent support as a core resource for families with children who have a special healthcare need, disability, or mental health concern. The organization matches and connects trained support caregivers to other caregivers who have the same or similar conditions to offer support via phone calls and email. Support parents are trained to provide a safe environment for the caregiver to share their experiences. They do not give any medical or professional counseling.

THE HEALTH ADVOCACY SUMMIT

The Health Advocacy Summit facilitates events and programs for adolescents and young adults with chronic and rare conditions. A program through the Health Advocacy Summit is the Crohn's and Colitis Young Adults Network, which facilitates support groups, around eight pieces of new content each month, and an international fellowship program for young adults with IBD.



Recreation, Vacation, and Travel

Families living with Crohn's disease can take vacations! Vacations can be a great way to manage emotional strain, even when there is grief. There are many ideas and options at different expense levels for a family managing Crohn's disease. Do not be afraid to take a vacation—it just takes research and planning.

Planning is key. Successful outings and traveling with a child with Crohn's disease may need even more preparation. With planning, your trip can build a wonderful memory for the family. Do not be shy about calling ahead to ask about travel needs, lodging, bathroom and meal accommodation, and anything else that is necessary.

Know ahead of time what you can pack in your bags on the flight on the TSA website at www.tsa.gov/travel/special-procedures. It is also helpful to bring a list of any prescription drugs your child is taking, a doctor's letter of your child's condition and needs in case of an emergency, and phone numbers of your home doctors and specialists. Your doctor may be able to recommend doctors or specialists in the area you are visiting in case of an emergency. Be sure to have insurance cards and review your insurance policy before the trip in case you need prior approval to visit an out-of-town doctor or emergency room. Most airlines allow priority seating for patients with medical conditions, which can be helpful if your child prefers an aisle seat or one near the bathroom.

Taking out travel insurance when going on long-distance trips can also be helpful in case you need to cancel because your child is sick. You can also get travel insurance with medical coverage, which is important especially when traveling outside the U.S. as your health insurance may not cover medical costs in another country.

Finally, recognize that the very best plans sometimes get interrupted by life with Crohn's disease. Do not expect perfection. If your trip goes sideways from the plan, be flexible and adapt and enjoy your precious family time.



SPIRITUALITY

Some caregivers of children with Crohn's disease lean on spirituality to overcome loneliness, anxiety, and depression, and to improve emotional wellbeing in general. Recognizing that caregivers are diverse in their belief systems, this guidebook does not prescribe a spiritual method. Instead, it encourages caregivers to lean onto their core spiritual beliefs for hope. Health providers and communities might suggest helpful resources. An accessible spiritual resource in health centers are chaplains or clergy members who have received training to support patients and families. Chaplains are typically trained to work across faiths and cultures and advocate for patients and families. Patients and families have a choice to access this service, and many find it helpful. However, caregivers can, at any point, choose to discontinue the relationship or to seek other supports, such as those offered by their faith communities, if they so choose to. The key is to access support services that are in agreement with the caregiver's core beliefs and decisions. If your spirituality leads you to explore alternative medicine for your child, be sure to consult your child's GI before pursuing this course of action.

Caregivers might explore some evidence-based spiritual practices, such as prayer, assigning a purpose or meaning to one's hardship,⁴⁶ and maintaining a gratitude journal.

FROM HOW CAREGIVERS CAN CULTIVATE MOMENTS OF POSITIVITY:⁴⁷

- **Noticing positive events:** Being aware of the good things in your life, an antidote to narrowly focusing on the negative.
- **Capitalizing on positive events:** A way of extending and savoring your good feelings, such as by telling someone else, writing them down, or remembering the event later.
- **Mindfulness:** Being aware of the present moment without judgment. Participants learn a guided mindful breathing exercise and incorporate mindfulness into daily activities, like brushing teeth and washing dishes.
- **Noting personal strengths:** Recognizing the personal resources you have at your disposal and how you enact them in your life, an antidote to feeling helpless.
- **Setting attainable goals:** Choosing aims that are challenging but not too challenging, allowing you to feel accomplished and successful.

www.greatergood.berkeley.edu/article/item/how_caregivers_can_cultivate_moments_of_positivity

⁴⁶Frankl, Viktor E. (Viktor Emil), 1905-1997. (1962). *Man's search for meaning; an introduction to logotherapy*. Boston :Beacon Press ⁴⁷Newman, K. N. (2015). *How Caregivers Can Cultivate Moments of Positivity*. Retrieved from https://greatergood.berkeley.edu/article/item/how_caregivers_can_cultivate_moments_of_positivity



RESPITE

From time to time, you will need a break from caring for your child with Crohn's disease. Even if the care of your child is shared with a spouse or paid help, you deserve some 'me time'. The more you take care of yourself, the better you will be able to care for your child. There are different types of respite care. These include a caregiver coming into your home, a day program your child visits, or a daily or weekly program hosted by a family, a residential facility, or a sleepaway camp. Respite care can be expensive, but, there are public and private programs that can help with funding. Access to Respite Care and Help (ARCH) is a respite care assistance organization that can be a useful resource in location of respite services and caregiver supports in your community, as well as guidance for funding. More information can be found at www.archrespite.org.

In addition to the programs and camps described previously, the following are two examples of respite retreats specifically for caregivers:

DAVID'S REFUGE

www.davidsrefuge.org/about-us

A faith-based organization located in upstate New York that provides respite, resources, and support to parents and caregivers of children with special needs or life threatening medical conditions. Additionally, they offer virtual support and resources on health and wellness, as well as spirituality.

A MOTHER'S REST CHARITABLE RESPITE FOUNDATION

www.amothersrest.org

A nonprofit charity that specializes in coordinating therapeutic respite retreats for parents of children with extra and special healthcare needs. Offers retreats to mothers and fathers to get away and address caregiver fatigue, both physiological and mental. The organization partners with nationwide hotels, inns, and lodging providers to make recuperative respite available and affordable for caregivers.

It is not uncommon for a caregiver to make career changes to be able to manage medical appointments, complex medical needs, and daily care necessary to care for a child with Crohn's disease.



BALANCING WORK AND CARE

Beyond the costs of medical care, the impact that Crohn's disease has on the income for the family is significant. Nearly all participating caregivers in our *National Study of Caregivers of Individuals with Crohn's Disease or Ulcerative Colitis* who worked outside of the caregiver relationship (94 percent) reported missing time at work because of caregiving, and more than half of working caregivers reported declines in their level of performance or productivity. It is not uncommon for a caregiver to make career changes to be able to manage medical appointments, complex medical needs, and daily care necessary to care for a child with Crohn's disease. A considerable number of caregivers of Crohn's disease children and adolescents have reported that they have also cut back on their hours, taken a leave of absence, turned down a promotion, or left the workforce altogether.⁴⁸ These options come with high costs that can financially devastate a family.

If you continue to work while caring for your child with Crohn's disease, it can be difficult to balance your career and the needs of your child. This is the case especially if you are a single-parent; peer-reviewed literature has shown that single parents experience greater stress than two-parent families affected by chronic illness.⁴⁹

Whether you are a single-parent or not, it is important to take time for yourself and allow others to help. If possible, involve the other parent and other family and friends in helping care for your child. Fitting in family time and counseling may also be helpful. There are many programs that offer counseling on a sliding scale,



⁴⁸https://www.caregiving.org/wp-content/uploads/2020/05/September-2019_National-IBD-Caregiving-Report_digital.pdf ⁴⁹Cousino, M. K., & Hazen, R. A. (2013). Parenting stress among caregivers of children with chronic illness: a systematic review. *Journal of pediatric psychology, 38*(8), 809-828.

and sometimes counseling can be covered by health insurance. Single parents may be eligible for Social Security benefits or other forms of financial assistance. All caregivers can also look to Family Responsibilities Protections as an option to help you balance caregiving and work. Keep in mind that protections may vary by state. Some employee protections for caregivers include:

- The Family and Medical Leave Act (FMLA): provides up to 12 weeks of unpaid leave and job protection for those caring for a spouse, child, or parent with a serious health condition. This law also provides unpaid sick leave with job protection in workplaces that must follow the FMLA.⁵⁰ Read more about how it works in the [Resources](#) section.
- Four states (California, New Jersey, Rhode Island, and Washington, D.C.) offer paid family and medical leave. Learn more about the benefits and what's available in other states in the [Resources](#) section.
- Five states (Alaska, Connecticut, New Jersey, Oregon, and Washington, D.C.) provide employment protection for family caregivers, although some cities may have ordinances that offer protection as well. Read about the existing benefits in the [Resources](#) section.

If possible, you may also want to talk to your manager and inform them of your caregiving responsibilities. While some companies have caregiving accommodations in place, others do not, so it's important to understand what resources your company is able

All caregivers can also look to Family Responsibilities Protections as an option to help you balance caregiving and work.

to offer you and that you can advocate for, and which ones they won't be able to provide you. Some example accommodations for caregivers include:⁵¹

- Adult day care;
- Change in work hours;
- Job sharing;
- Leaves of absence;
- Therapy options through health insurance.

A Place for Mom has more helpful tips on how to talk to your employer about your caregiving responsibilities. Check out the full article in the [Resources](#) section.



The Family and Medical Leave Act (FMLA): provides up to 12 weeks of unpaid leave and job protection for those caring for a spouse, child, or parent with a serious health condition.

⁵⁰<https://www.dol.gov/agencies/whd/fmla> ⁵¹<https://www.aplaceformom.com/caregiver-resources/articles/talk-to-employer-about-caregiver-needs>



RESOURCES

General Resources About Crohn's

Crohn's disease overview

<https://www.crohnscolitisfoundation.org/what-is-crohns-disease/overview>

Information for parents and caregivers

<https://www.crohnscolitisfoundation.org/what-is-crohns-disease/overview>

<https://www.crohnscolitisfoundation.org/community-support/ibd-help-center>

www.caregiving.org/ibd

<https://www.crohnscolitisfoundation.org/youth-parent-resources>

Information specifically for children and adolescents

<https://www.crohnscolitisfoundation.org/sites/default/files/legacy/assets/pdfs/ibd-me-ac.pdf>

<https://www.crohnscolitisfoundation.org/justlikeme>

Relationships

"When Your Chronic Illness Reveals Who Your True Friends Are", The Mighty: <https://themighty.com/2015/12/when-your-chronic-illness-reveals-who-your-true-friends-are/>

"Dating with Crohn's Disease", Everyday Health: <https://www.everydayhealth.com/columns/my-health-story/dating-with-crohns-disease/>

Lilly's story: https://online.crohnscolitisfoundation.org/site/SPageNavigator/awareness_hero_lilly.html;jsessionid=00000000.app330a?NONCE_TOKEN=F48B2DEA8A23362E89F8C4107BC025FC&hss_channel=fbp-101393913279829&utm_medium=social&utm_content=80652198&utm_source=facebook&utm_campaign=Awareness%2520%20Week%25202018

"Social Life", The Crohn's and Colitis Foundation: <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/social-life>

Diet and Nutrition

Specific carbohydrate diet: <https://med.stanford.edu/content/dam/sm/gastroenterology/documents/IBD/CarbDiet%20PDF%20final.pdf>

Mediterranean diet: <https://www.crohnscolitisfoundation.org/diet-and-nutrition/special-ibd-diets>

Crohn's disease exclusion diet (CDED): <https://ntforibd.org/therapeutic-diets/crohns-disease-exclusion-diet/>

IBD-aid diet: <https://www.umassmed.edu/nutrition/ibd/ibdaid/>

"Malnutrition and IBD", The Crohn's and Colitis Foundation:
<https://www.crohnscolitisfoundation.org/diet-and-nutrition/malnutrition-and-ibd>

Food allergy information: <https://www.foodallergy.org/>

Clinical Trials

The Crohn's and Colitis Foundation, <https://www.crohnscolitisfoundation.org/clinical-trials-community/pediatric-clinical-trials>

<https://clinicaltrials.gov/>

Support Groups

Crohn's Forum, <https://crohnsforum.com/>

IBD Support Foundation, <https://ibdsf.org/index.php/programs-services>

The Crohn's and Colitis Young Adults Network facilitates support groups, around eight pieces of new content each month, and an international fellowship program for young adults with IBD:
www.ccyanetwork.org

Ask your GI about local support groups

Camps and retreats for children

<https://www.crohnscolitisfoundation.org/get-involved/camp-oasis>

<https://www.girlswithguts.org/retreats>

www.healthadvocacysummit.org

<https://ostomyconnection.com/news-and-culture/summer-camp-for-children-and-teens-ostomy>

Resources for Taking IBD to School

"Taking IBD to School", The Crohn's and Colitis Foundation,
<https://www.crohnscolitisfoundation.org/youth-parent-resources/kids/taking-ibd-to-school>

"504 Plan and Individualized Educational Plan fact sheet", The Crohn's and Colitis Foundation, <https://www.crohnscolitisfoundation.org/sites/default/files/2019-07/school-accommodation-12-16.pdf>

Information on eligibility for college-entrance testing accommodations, The College Board, <https://accommodations.collegeboard.org/eligibility>

Information on university disability support, The Crohn's and Colitis Foundation, <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/disability-support>

Patient Advocacy Organizations and Chapters

Crohn's and Colitis Foundation,
<https://www.crohnscolitisfoundation.org>

ImproveCareNow, https://www.improvecarenow.org/join_circle_signup

Crohn's Forum, <https://crohnsforum.com/>

United Ostomy Associations of America, <https://www.ostomy.org>

International Foundation for Function Gastrointestinal Disorders (IFFGD), <https://www.iffgd.org/>

The American Gastroenterological Association of America (AGAA),
<https://gastro.org/>

North American Society for Pediatric Gastroenterology, Hepatology & Nutrition (NASPGHAN), <https://naspghan.org/>

The Health Advocacy Summit, www.healthadvocacysummit.org

The Crohn's and Colitis Young Adult Network, www.ccyanetwork.org

Caregiving-Specific Organizations

The National Alliance for Caregiving, www.caregiving.org/ibd

Arch Respite, www.archrespite.org

Family Caregiver Alliance, www.caregiver.org

Caregiver Action Network, www.caregiveraction.org

Rosalynn Carter Institute for Caregivers, www.rosalynncarter.org

Caring Across Generations, www.caringacross.org

Administration for Community Living, www.acl.gov

Mental Health

The Crohns and Colitis Foundation: search for a mental health provider under "Find a Medical Expert" link at <https://www.crohnscolitisfoundation.org/find-a-medical-expert>

Rome Foundation PsychoGastro mental health provider directory:
<https://romegipsych.org/>

Psychology Today: <https://www.psychologytoday.com/us/therapists>

National Alliance on Mental Illness: www.nami.org

“Coping Strategies for Better Mental Health”, The Crohn’s and Colitis Foundation, <https://www.crohnscolitisfoundation.org/mental-health/coping-strategies-for-better-mental-health>

Care Coordination and Finding Medical Experts

“Find a Medical Expert”, The Crohn’s and Colitis Foundation, <https://www.crohnscolitisfoundation.org/find-a-medical-expert>

Care Centers, ImproveCareNow, <https://www.improvecarenow.org/care-centers>

Information on care coordination, Agency for Healthcare, Research & Quality, www.ahrq.gov/ncepcr/care/coordination.html

“IBD Patient-Centered Medical Home Delivers Multidisciplinary Care”, The Cleveland Clinic, <https://my.clevelandclinic.org/podcasts/butts-and-guts/ibd-patient-centered-medical-home-delivers-integrated-multidisciplinary-care>

“Medical Homes for Patients with Inflammatory Bowel Disease,” National Institutes of Health, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5495046/>

Transitions of Care

“Discharge Checklist”, Agency for Healthcare Research and Quality (AHRQ) IDEAL, www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy4/Strat4_Tool_1_IDEAL_chklist_508.pdf

“Hospital Discharge Planning Guide for Families and Caregivers”, Family Caregiver Alliance, www.caregiver.org/hospital-discharge-planning-guide-families-and-caregivers

“Your Discharge Planning Checklist”, Centers for Medicare and Medicaid (CMS), www.medicare.gov/pubs/pdf/11376-discharge-planning-checklist.pdf

Transitioning to College as a Crohn’s Patient

Information and tips on navigating college, The Crohn’s and Colitis Foundation, <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college>

Tips on choosing your college, The Crohn’s and Colitis Foundation, <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/choosing-your-college>



Information on managing care costs at college, The Crohn’s and Colitis Foundation, <https://www.crohnscolitisfoundation.org/campus-connection/beyond-college/managing-care-costs>

Tips for studying abroad, The Crohn’s and Colitis Foundation, <https://www.crohnscolitisfoundation.org/campus-connection/navigating-college/studying-abroad>

Scholarship Opportunities

<https://www.crohnsandcolitis.com/scholarship>

<https://www.abbvieimmunologyscholarship.com>

Entering the Workforce as a Crohn’s Patient

Americans with Disabilities Act (ADA) information, https://www.ada.gov/ada_fed_resources.htm

Resources for Other Family Members

The effects of IBD on parents and siblings, The Crohn’s and Colitis Foundation, http://online.crohnscolitisfoundation.org/site/DocServer/IBDparentsandsiblings.pdf;jsessionid=00000000.app30038a?docID=32087&NONCE_TOKEN=EA033B17A297724A5D4B3FD452603D3E

“10 Great Books for Talking About Surgery Sickness and Feelings”, Health Blog, <https://healthblog.uofmhealth.org/childrens-health/10-great-childrens-books-for-talking-about-surgery-sickness-and-feelings>

Sibling support, SibShops, <https://siblingssupport.org/sibshops/>



Travel

What you can bring on an airplane, TSA, <https://www.tsa.gov/travel/special-procedures>

Which vaccines or medications are needed to travel abroad, Center for Disease Control and Prevention, <http://www.cdc.gov/travel>

Working While Caregiving

“Talk to Your Employer About Caregiver Needs”, A Place for Mom, <https://www.aplaceformom.com/caregiver-resources/articles/talk-to-employer-about-caregiver-needs>

Family Medical Leave information, National Conference of State Legislatures, <https://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx>

The Employee’s Guide to the Family and Medical Leave Act, U.S. Department of Labor, <https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/employeeguide.pdf>

“Protecting Caregivers from Employment Discrimination,” AARP, https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/protecting-caregivers-employment-discrimination-fs-AARP-ppi-ltc.pdf

Cost of Care and Access

Air Charity Network, www.aircharitynetwork.org

American Cancer Society, www.cancer.org

Benefits, www.benefits.gov

Care Calendar, www.carecalendar.org

Catastrophic Illness in Children Relief Fund in Massachusetts, www.mass.gov/catastrophic-illness-in-children-relief-fund-cicrf

Catastrophic Illness in Children Relief Fund in New Jersey, www.state.nj.us/humanservices/cicrf/home/

Children’s Flight of Hope, www.childrensflightofhope.org

Children’s Health Insurance Program, www.healthcare.gov/medicaid-chip/childrens-health-insurance-program

Children’s Inn at NIH, www.childrensinn.org

Good Days, www.mygooddays.org

Healing the Children, www.htcne.org

HealthWell Foundation, www.healthwellfoundation.org

Hemophilia Federation of America, www.hemophiliafed.org

Hospitality Homes, www.hosp.org

Meal Train, www.mealtrain.com

Medicaid, www.medicaid.gov

Mercy Medical, www.mercymedical.org

Miracle Flights, www.miracleflights.org

National Alliance on Mental Illness, www.nami.org

National Cancer Institute, <https://supportorgs.cancer.gov/home.aspx?js=1>

Needy Meds, www.needymeds.org

PALS, www.palservices.org

Patient Services, Inc. www.patientservicesinc.org

Ronald McDonald House, www.rmhc.org

RxAssist, www.rxassist.org

Social Security, www.ssa.gov/disability

Take Them a Meal, www.takethemameal.com

Title V funding, www.mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program

Wings of Hope, www.wingsofhope.ngo

Family and Medical Leave Act (FMLA), <https://www.dol.gov/agencies/whd/fmla>



GLOSSARY

Accommodations for Children and Adolescents with Crohn's Disease

504 Accommodation Plan

Educational accommodation that allows your child's needs—based on their Crohn's disease—to be met at school. You and your child can negotiate the 504 accommodation plan and, once in writing, it will be in effect for an entire school year.

Individualized Educational Plan or IEP

An IEP is a plan used by children with an intellectual or learning disability and who require specialized teaching. An IEP is available to students in need though the Individuals with Disabilities Education Act (IDEA). A student who has an intellectual or learning disability, in addition to Crohn's disease, may incorporate their 504 accommodation(s) into the IEP.

American with Disabilities Act

Civil rights law that prohibits discrimination against individuals with disabilities.

Healthcare

Crohn's disease

A subset of inflammatory bowel disease (IBD), which is a chronic autoimmune and inflammatory condition of the gastrointestinal tract with increasing incidence worldwide. The disease can occur at any age, but, Crohn's disease is often diagnosed in children, adolescents, and very young adults.

Inflammatory bowel disease or IBD

A chronic inflammatory autoimmune condition of the gastrointestinal tract with increasing incidence worldwide. Crohn's disease is a type of inflammatory bowel disease.

Ulcerative colitis or UC

Another form of inflammatory bowel disease which primarily causes inflammation in the colon and the rectum.

Indeterminate colitis

If doctors are unable to distinguish between Crohn's disease and ulcerative colitis in a patient, providers may diagnosis the patient with indeterminate colitis, especially if the inflammation and ulcerations are only present in the colon and rectum and without the typical penetrating features and skip lesions that Crohn's patients may have.

Ileum

The end of the small intestine.

Irritable bowel syndrome or IBS

A disorder of gut-brain interaction (DGBI) that can also occur in patients with IBD and can often be mistaken for IBD symptoms.

Terminal ileitis

An inflammatory condition of the terminal portion of the ileum that may occur acutely with right lower quadrant pain and is normally associated with Crohn's disease.

Colonic Crohn's disease

Colonic complications of Crohn's disease include hemorrhage, fulminant colitis, abscess or fistula, stricture, and malignant transformation.

Complications and Manifestations in Crohn's Disease

Abscess

A collection of pus caused by bacterial infection.

Bowel perforation

The development of a hole anywhere along the gastrointestinal tract resulting from severe inflammation.

Fistulizing disease

Complications of Crohn's that cause damage to the lining of the intestines and result in abscesses and abnormal tunnels between the intestine and another organ (e.g., bladder), or out onto the skin.

Stricturing disease

A narrowing of the intestine from inflammation preventing stool from passing through, possibly resulting in intestinal blockages and sometimes bowel perforations.

Toxic megacolon

A complication of ulcerative colitis that causes the colon to expand, dilate, or distend, preventing it from eliminating waste from the body. This may eventually result in the colon rupturing and the development of sepsis.

Sepsis

A serious condition that occurs when the body's response to an infection damages its own tissues.

Pseudopolyps

A complication of IBD in which the cycle of ulceration and healing in IBD results in scar tissue. Scar tissue that forms from severe inflammation often heals to resemble a polyp.

Anemia

A potential complication of Crohn's disease resulting from low iron levels and poor absorption of vitamins and minerals.

Osteopenia

The beginnings of the loss of bone mass.

Osteoporosis

Loss of bone mass and low bone density.

Extraintestinal manifestation (EIM) of IBD

Occurs when IBD affects a part of the body outside the intestines. EIMs account for most comorbidities in IBD.

Comorbidities

Individuals living with Crohn's disease may live with another disease other than IBD (comorbidities), including rheumatoid arthritis, ankylosing spondylitis, psoriasis, among others, including psychiatric comorbidities.

Sacroiliitis

Inflammation of the sacroiliac joint that can cause chronic lower back pain.

Ankylosing spondylitis

Inflammation and arthritis of the spine.

Uveitis

Inflammation of the uvea in the eye.

Scleritis

Inflammation of the white of the eye.

Episcleritis

Inflammation of the outer coating of the white of the eye.

Keratopathy

Abnormality of the cornea.

Dry eyes

A secondary problem that can be associated with any of the above conditions, vitamin A deficiency and/or eye allergies.

Primary sclerosing cholangitis (PSC)

Inflammation in the bile ducts which causes scarring and could lead to cirrhosis down the line.

Hepatitis

Can coexist as another autoimmune disorder with IBD and leads to inflammation of the liver.

Cholecystitis

Inflammation of the gall bladder mostly due to gallstones blocking the bile duct.

Non-alcoholic fatty liver disease (NAFLD)

Can occur when extra fat gets deposited in the liver.

Hydronephrosis

An obstruction of one of the ureters—the tubes connecting the kidney to the bladder.

Fistulas

Abnormal tracts between the intestines and adjacent organs, including the bladder or ureter. These can cause urinary tract infections and sepsis, and may require close monitoring and immediate care.

Glomerulonephritis

Inflammation in the kidney that limits its filtering ability.

Amyloidosis

An abnormal deposit of protein into the kidneys.

Testing and Procedures

Colonoscopy

A test used to check changes or abnormalities in the colon.

Biopsy

A test used to examine tissue microscopically to determine the cause and degree of inflammation.

Capsule endoscopy

A procedure that uses a tiny wireless camera to take pictures of the gastrointestinal tract, and mainly the small intestine.

Magnetic resonance imaging (MRI)

A medical imaging technique used in radiology to form pictures of organs and tissues in one's body without radiation exposure.

Computerized tomography (CT) scan

A medical imaging technique used in radiology to form pictures of organs and tissues in one's body.

DEXA

Bone density scan done in IBD patients regularly to ensure that proper bone density is maintained.

Treatment**Remission**

Characterized by a decrease or disappearance in IBD symptoms. Remission has a variety of meanings for IBD patients and their caregivers. As such, the term remission is best described as a variety of types of remission.

Exclusive enteral nutrition (EEN)

May be the recommended first-line therapy to treat active Crohn's disease. EEN is a nutrition-based formula delivered either orally or via feeding tube.

5-ASAs/Aminosalicylates

Aminosalicylates may be prescribed to control inflammation in the lining of the digestive tract. They are mainly used to treat mild to moderate ulcerative colitis, but, due to lack of efficacy, many gastroenterologists have moved away from using 5-ASAs to treat Crohn's disease. Aminosalicylates may come in the form of pills, enemas, or suppositories inserted through the rectum. The type taken depends on several factors, including where in your digestive tract the inflammation is located. 5-ASA drugs are prescribed for maintenance treatment and are used to prevent flares of the disease. They need to be taken for many years, even when the patient may be feeling better and having few, if any, symptoms or flares.

Corticosteroids

Corticosteroids are hormones produced by the adrenal glands. They have many important functions in the body, including control of inflammatory responses.

Steroid medications are anti-inflammatory and work by suppressing the immune system. Steroids may be helpful in IBD flares and are often used as a bridge to a more longer-term medication therapy in IBD. Steroids are not helpful in preventing future flares and should not be taken for long periods of time due to their side effect profile. In some cases, using steroids for longer timeframes might result in complications of Crohn's disease, including abscesses and fistulae. Most steroid medications for IBD come in pill form, but, they can also be administered rectally as an enema, suppository, or foam. In acute flares and hospitalizations, steroid infusions are also possible.

Antibiotics

In some cases, the inflammation in IBD may be caused by the proliferation of intestinal bacteria. By killing off and controlling the growth of such bacteria, antibiotics may help to curb IBD flares. Antibiotics may also be used to prevent bacterial growth and sepsis caused by complications of Crohn's disease, including abscesses, fistulae, and strictures.

Immunomodulators

Immunomodulators work to calm the overly active immune response that results in Crohn's-related inflammation. They are most often used in moderate to severe Crohn's disease. There are oral immunomodulators, as well as injectable ones. These medications can take approximately 2 to 3 months to start working, so, steroids and EEN are often used in the interim to keep the disease at bay. This class of medication can be effective in maintaining steroid-free remission in moderate –to severe cases of IBD. Unlike steroids, these medications can be used safely for a long time. It is important to continue the immunomodulator even when feeling well. Immunomodulators were initially developed as treatments for cancer and while they carry some side effects, this class of medication may be needed to treat the patient's brand of IBD. It is best to speak to your child's gastroenterologist recommending this medication to understand the risk-benefit profile.

Biologics

Biologics are antibodies developed in the laboratory that stop certain proteins in the body or in the gut from causing inflammation. Biological therapies offer mechanisms of action that are more precisely targeted to the pathways that may result in Crohn's-related inflammation. Biological therapies are often used to treat moderate –to severe cases of Crohn's disease. They can come in the form of injectables and/or intravenous infusions.

Biologics are generally considered steroid-sparing therapies in that they have a better safety profile than most corticosteroids, and are often used in long-term treatment to prevent disease relapse and induce remission.

There are many different pathways that biologics currently target and many more in the pipeline waiting to be developed and tested. Some common pathways include anti-TNF (tumor necrosis factor), anti-integrin (gut-focused biologics), and anti-IL-12/IL-23 agents. Each biological agent works differently and has been studied for different variations of disease activity (e.g., one may have better data for treating fistulizing Crohn's versus another). Each one also has a different side effect profile. It is always best to discuss which option may be the optimal fit given your child's disease presentation and location with the gastroenterologist.

Biologics are often expensive to develop, may require additional insurance prior authorizations, and are often costly for patients to afford. It is best to consult your doctor's office, insurance specialty pharmacy program, and the pharmaceutical company for patient assistance programs. It is important to note that there is currently only one pathway that is FDA-approved for pediatric patients.

Small molecules

In IBD, small molecules refer to organic compounds that are directed at specific inflammation-causing pathways. Small molecules are generally used to treat moderate –to severe IBD. They mostly come in oral form, unlike biologics, making them more patient-friendly. Some of the more well-known small molecule medications in the IBD world inhibit or mediate the following pathways: Janus-Kinase (JAK inhibitors), which is FDA-approved for ulcerative colitis, and sphingosine-1-phosphate (S1P receptors) which is not yet FDA-approved. There are other molecules currently in development.

Each small molecule therapy works differently and has a different safety and side effect profile. It is best to discuss which option may be optimal for your child with their gastroenterologist.

Ostomy

External collection of feces into a pouch.

Proctocolectomy

Removal of the diseased colon or rectum.

Hemicolectomy

Removal of a portion of the diseased colon.

Resection

Removal of a diseased or strictured portion of the small or large intestine.

Colostomy

A type of ostomy usually given in hemicolectomies where a portion of the colon is salvageable.

Anastomatic leak

Leaks can sometimes happen at the site of a surgical resection. This can result in sepsis and can require immediate surgery to correct.

Proactive disease management

Proactive disease management involves checking medication levels and disease activity to ensure Crohn's disease is well controlled.

Treat-to-target approach

This approach focuses on utilizing advanced therapies early on and continually monitoring the levels of those medications in order to achieve mucosal healing and long-term remission in IBD patients.

Therapeutic drug monitoring or TDM

Continually monitoring levels of medication in a patient's bloodstream in order to achieve mucosal healing and long-term remission in IBD patients.

Diet and Nutrition**Specific carbohydrate diet or SCD**

Eliminates refined and processed foods along with grains, fibers, and some sugars

Mediterranean diet

Focuses on foods rich in fiber, as well as plant-based foods, including olive oil, low-fat dairy, herbs, and spices. Eliminates red meat and recommends poultry, eggs, yogurt, and cheese in moderation.

Crohn's disease exclusion diet or CDED

Includes a whole-food diet—fruits, vegetables, meats, and complex and simple carbohydrates—along with enteral nutrition designed to reduce dietary exposure to foods that may negatively impact the microbiome and the intestinal barrier.

IBD-AID diet

Avoids certain carbohydrates, similarly to SCD, that are pro-inflammatory and that may be disturbing the normal gut flora. Foods that contain lactose, wheat, refined sugar (sucrose), and corn are avoided in all phases of the diet. There are phases in this diet that allow for reintroduction of foods as the gut heals.

Enteral nutrition or EN

A way to bring nutrition into the body to stay healthy. Enteral nutrition is usually taken in the form of a nutrient-rich formula via oral ingestion or via feeding tube.

Partial enteral nutrition

Refers to using enteral nutrition as a supplement to caloric intake.

Avoidant restrictive food intake disorder or ARFID

A disorder in which a patient manifests signs and symptoms of post-traumatic stress (PTS) around food they believe may harm their body.

Vaccines**Live attenuated vaccine**

Live, attenuated vaccines contain the active virus in a weakened state. Patients on immunosuppression of any kind may not be able to receive live, attenuated vaccines.

Inactivated vaccines

Inactivated vaccine contain the virus, but, in a dead state.

Empowering Your Child to Manage Their Crohn's Disease**Shared decision-making**

Occurs when health professionals—IBD specialists, registered dietitians, and sometimes GI psychologists/social workers—work together with the pediatric caregiver(s) and patient to decide upon a course of action they feel most comfortable taking to treat the patient's IBD.

Flare-up

When IBD symptoms are active

Assent

In the context of healthcare, assent is used when a child is under the age of 18 and unable to legally give "consent". When a child assents to something, it means they understand and have given their approval.

Consent

At the age of 18 in the United States, persons are legally allowed to give their consent when it comes to healthcare matters without the approval of a parent or guardian. At this stage, children may still consult their parent or guardian but they will ultimately have the right to control their treatment plan.

Care partner

When a child turns 18, or in some cases even before the age of 18, a parent or guardian transitions into the role of "care partner" instead of sole caregiver. This means that the child is taking an active role in their care and decision making process but still works closely with their parent or guardian to manage their care.

Empower Your Child to Manage Their Crohn's Disease!





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National Alliance for Caregiving

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. NAC conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, NAC supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at www.caregiving.org.