

# A Parent's Guide to Inflammatory Bowel Disease



How to handle dietary needs and digestive symptoms in school and in social situations from childhood through college

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# Introduction

You are reading this because you have at least one child with Crohn's disease or ulcerative colitis or another condition affecting their digestion. I was that child, many years ago and my parents were in the same position you are. I'm not a kid anymore (although I wish that weren't the case), but I am not a parent, yet, either. I have made it to the other side that is adulthood, all while navigating Crohn's disease, a diagnosis I was given at the age of 12.

I know that receiving an autoimmune diagnosis can be scary, disheartening, and worrisome. However, it is also the most liberating thing that can happen to someone who has been sick. It enables you to take charge of your (or your child's) health.

As someone diagnosed in my pre-teenage years, I can speak to how having IBD impacted my academic and school life throughout the years. One thing is for sure, having supportive parents that advocated for me was essential. I didn't realize their impact at the time; I thought it was just their job! I never felt truly alone because when we hit a bump in the road they brainstormed until we had a solution.

Teachers, friends, and family all want to be helpful, but they don't always know how. That's why reaching out and having conversations is so important. Not only will you educate everyone involved in your child's life, but you are lightening the load off of your child's shoulders.

To create this guide, I spent a lot of time thinking about my younger self when I was diagnosed with Crohn's, then in middle school, high school, and lastly, college. I reflected on what we did that was helpful and what made me feel good. I hope my experiences give you some ideas about how to handle IBD in school and social situations with your child!

# IBD in Childhood

(through elementary school)

Although no one wants their child to have a chronic illness, there are some positives about being diagnosed earlier rather than later in life.

- The way you speak and handle the illness is going to influence your child. You have the power to shape their perspective. Speak simply about what the disease is and what will be different now. Don't show your child fear or negativity.
- Your child will learn to understand his/her body at a young age. This innate skill is lost among most adults today.
- Your child will learn how to advocate for themselves, especially when it comes to ordering at restaurants and reading food labels.
- When dietary and lifestyle changes are made at a younger age, that is the new "normal," and the transition is smoother.

## IBD & Food in Childhood

- Search online for blogs to bookmark and cookbooks to buy that fit in with your child's dietary needs. There is nothing wrong with using recipes already proven to work that are also enjoyable.
- Swap out your child's favorite foods/ingredients for compliant ones. Ex: For grain-free try zucchini, kelp, or sweet potato noodles. If you can replicate these favorite dishes closely enough, you will have some staple meals you know your child will always eat.
- Bring your child to the grocery store. When I was younger and got bored with my diet, I would go to Whole Foods or my regular grocery stores and peruse the aisles for new foods. I would always find something new to try and I felt inspired to keep eating aligned with my diet. If finances are tight, allow your child to pick out 1-2 items to try each trip.

- Have your child help you prepare the food. When children take part in making food, it means so much more than when they sit down to a dinner only you made. Plus, they will get comfortable in the kitchen, which will only become more useful as they get older.
- Prep and freeze! Once you have some tried and true recipes your child loves, make a batch of each and freeze them. This can be casseroles, soups and stews, precooked meats, muffins, breads, and treats for last minute occasions. This strategy will not only be helpful to you as a time-saver, but there are going to be days when nothing sounds appealing to eat, or your child is craving dessert and you can pull from the freezer stash.

## **IBD & School in Childhood**

- Right away, communicate with the school principal, the secretary, your child's teacher, and all other staff that may work with your child, such as aids, nurse, lunch staff, teachers of specials, etc. Call and set up an appointment. Ask your child's doctor for a note outlining the manner of the condition and any forms of support he/she may need.
- Forms of support can include: being allowed to go to the bathroom without asking in cases of emergency, home tutoring if enough school days are missed, testing in a separate room and/or extended testing times, etc.
- See if you can keep a couple of treats or snacks in the classroom and/or in the nurses's office in case your child ever forgets food or there is a special occasion where students are having treats.
- Supply the school nurses with any medications (daily and/or emergency/antidiarrheal) that your child may need during the school day as well as a heating pad and an extra set of pants and underwear in case of an accident.
- It will be easier to pack a safe lunch, but if your child wants to buy, see what can be done by talking with the lunch staff.

- Many schools have "parties" during holidays or for student birthdays. Ask the teacher for a list of classroom birthdays so you can be prepared to bring in a safe treat for your child when cookies or cupcakes are passed around. Bring a cupcake, pizza or any other food that makes sense for birthday parties outside of school, too.
- If your child is 100% okay with it, ask your teacher if you can come into the classroom and teach the children about IBD (or the condition your child has). This can help the students understand why your child might miss school, not feel well, or not be able to eat all of the same foods as the rest of the class.

### **IBD & Family/Friends in Childhood**

- Whether your child wants people to know about his/her IBD or not, it's important to keep the parents of close friends informed when they are supervising your child.
- Keep an extra set of pants and underwear at friends' houses your child frequents the most. Leave several choices of snacks for playdates and sleepovers. This will make your child feel more normal and it also takes the pressure off of the parent hosting. If your child uses any emergency medications or supplements, leave these at the friends' houses, too.
- If your child has strong reactions to foods and you want to minimize any risk of ingesting anything not right, leave a list of foods not allowed and a list of compliant foods.

**In summary:** Educating teachers and other caregivers about what to expect and how to handle your child's condition is critical. Also, doing what you can to make your child not feel left out among peers is so important for healthy, happy kids.

# IBD in Adolescence

(middle school to high school)

Adolescence is hard time for kids and parents alike, even before you add in health issues. This is the age I was diagnosed with Crohn's. I despised having to change my diet and avoid my favorite foods, but I stuck with it because I never wanted to be as sick as I had been ever again. There were times I wanted to give up. My parents were there to make sure I didn't until I was older and wanted to keep living a healthy lifestyle on my own.

## IBD & Food in Adolescence

- Every tip from the previous section applies here, but you can add on and make adjustments to each as it's appropriate.
- For example, middle and high schoolers are great at technology. Let them look up recipes they would enjoy from blogs. Compliant cookbooks make great gifts. Preparing meals that they love with substitutions is just as important at this age. Adolescents have busy lives and need lots of good food to grow and they may not have an interest in cooking for themselves yet.
- When they are old enough to drive, they can visit the grocery store on their own to find snacks, if they prefer.
- Encourage them to leave food at their friends' houses.
- They are clearly old enough to notice differences in adjusted recipes. Never lie that you are serving the original version of a dish. Rather, explain you are experimenting making a new version of X recipe and test it out together. Don't take it personally if they dislike it.

## IBD & School in Adolescence

- If your child is comfortable, he/she can tell the teachers about having IBD and provide them with a letter from the doctor. Conversely, you can contact the principal who can inform your child's teachers, if appropriate. This will be necessary if your child

may need to leave the classroom abruptly.

- Your child may want to leave a heating pad, medications or supplements, or a change of clothing with the nurse.
- Often, there are more lunch choices in middle and high school cafeterias, so buying lunch may work. Encourage your child to ask about ingredients in the food and let the cafeteria staff know what ingredients he/she is trying to avoid.
- Classroom parties are much less common, if they even exist at your child's middle or high school, than in elementary school, so it will likely be easier to avoid food-focused situations at this age in school.
- If a significant amount of school is missed, contact the school to set up private tutoring.

### **IBD & Friends/Family in Adolescence**

- This is the age where kids want freedom. They start going to restaurants, the mall, movie theater, etc. with friends and without parents.
- Encourage your child to take note of where bathrooms are when they go to a new public place. You can actually order a card that states your child has a disability that qualifies him/her to use any bathroom and cut the line.
- Have a collection of menus for nearby restaurants so you can always check what places will be easiest to eat at, or what your child can order if all of his/her friends are going to a particular place.
- You or your child can always call restaurants and ask questions that will make the dining experience less stressful, like asking if substitutions can be made and if measures are taken to avoid cross-contamination.

**In summary:** Adolescents can be rebellious. You may experience pushback from your child about being different, anger about having IBD, or not wanting to follow a certain diet. Your role as a parent and advocate is crucial here. Continue to support them but don't push them.

# IBD in College

Your child may be an adult now, but don't throw them to the wolves just yet! While it is important that they advocate for themselves at this age, your support will be helpful during this new and sometimes stressful time in their lives. Colleges and universities must comply with the Americans with Disabilities Act (ADA). There should be a department that only deals with setting students up with the disability services they qualify for.

## IBD & Eating in College

- If your child is commuting to school, then the food situation is much more simple. They can continue bringing food prepared at home to school if they have long days.
- Often, freshmen living at school do not qualify for housing with private kitchens. There are usually communal kitchens, however. If your child is comfortable, send them to school with minimal cooking equipment (one pot, one pan, some utensils, etc.) so that they can cook for themselves. You or your child can contact the ADA services at the school to ensure that the housing has cooking appliances. You can also try asking for housing that is apartment-style and has a kitchen. Since this is normally for older students, it may not be ideal for a freshman.
- Talk with the cafeteria staff. The summer before I entered my freshman year, my parents and I met with the person in charge of the food service company. He gave us a tour of the cafeteria and showed me where there was a fridge and pantry for allergy-friendly food. He was gracious and told me to let him know any products I wanted stocked, such as gluten free breads, frozen meals, non-dairy milks, etc. He also encouraged me to call the cafeteria an hour or more in advance if I wanted something special, like a gluten free pizza or burger without a bun. The staff can be very helpful if you ask. Don't be shy about proposing your own ideas as well. They don't know as well as you and your child what will be most helpful.



- When we think of college food, we think pizza, chicken fingers, and anything else fried that you can have delivered. Look for healthier frozen versions of these foods that your child can make in the dorm while his/her friends are eating these foods.

## **Housing**

- Although I did not have a private kitchen my freshman year, with the help of my parents I did communicate my need for a dormitory with a private bathroom. I was not at all comfortable sharing a communal bathroom with an entire floor of college students I didn't know. I was granted this, and it was the best decision for my happiness and comfort.
- In later years I lived in apartment-style housing with a private bathroom and full kitchen. Having my own kitchen was a huge help. As much as the cafeteria was accommodating, having a kitchen gave me so much freedom. I could go grocery shopping and make anything I wanted at any time.
- At my school, those who qualified for disability services chose their housing first, since they had certain needs that had to be met before the rest of the students.

## **Other Disability Services**

- If appropriate, your child can get extended testing time, a notetaker in class, the option to test in a separate room, extended due dates, and other forms of support.
- Often, freshmen are not allowed to have cars on campus. If this is the case, but you and your child feel that a car is necessary, you can take that up with disability services.

## Social Scenarios

- Of course, alcohol becomes the center of a lot of college social scenes. Alcohol can be irritating to the gut and promote inflammation, but depending on the individual with IBD it may be consumed occasionally with minimal effects (once of age, of course).
- The alcohol industry is not held to the same standards as the food industry. They do not have to publicize the ingredients in their products. This makes navigating alcohol difficult since a lot of alcohol is made from wheat, corn, soy, or other grains that are commonly irritating to IBD. I have reached out to companies asking for ingredients only to be told that is proprietary. Trial and error is the only way to know what works for each person.
- Colleges also offer plenty of activities on campus without food or alcohol. There is always some kind of event going on, even on the smallest campuses. Game nights, movie showings, and volunteer opportunities are abundant. Plus, there are a variety of clubs to join. Any club can be created, too, if one doesn't exist and it gets approved!
- Additionally, it's important for your child to remember the having IBD means you need to take extra care of yourself. Remind them that it's okay to stay in sometimes just to relax and wind down. It's tempting to try to maintain a super active social life, but to ensure that grades and health stay in check, down time is important.

**In summary:** College is when your child has more opportunities to advocate for themselves. Don't forget that college is also a completely new experience and he/she will be dealing with new kinds of stress, higher academic expectations and keeping up a social life, all with IBD.