

everyday life with IBD

People with IBD can live happy, healthy lives. A little preparation and planning can help make you more comfortable at school, when you travel, and at work (if relevant). This binder contains a high level overview of handling these situations. We encourage you to go online at the links listed for more information and resources.

section 504 plans for K-12

Children with IBD may miss school for medical appointments, illness, disease flare-ups, and side effects of treatment. A **section 504 plan** is used to help educate and inform your school of your symptoms and any accommodations you may need. The basics of the letter include an overview of IBD, an introduction to the plan, the students' symptoms and needs, and emergency contacts.

The Crohn's & Colitis Foundation recommends that all students with IBD have a 504 plan in place at the beginning of the school year, even if they are feeling well. Your child can be symptom free (in remission) at the beginning of the school year, but may experience active symptoms (flare up) later in the school year. Just because you have a plan in place, does not mean you must use all of the accommodations.

What is a 504 plan?

Section 504 of the Rehabilitation Act of 1973 enables students with disabilities to receive accommodations to ensure academic success and flexibility in their learning environment. It should contain a list of accommodations, or adjustments, which may be required by a child with IBD to ensure that they are treated fairly and have the same access to education as other students. This law typically applies to public schools – but can also apply to private schools, if the school receives federal funding.

A 504 plan is developed by the legal guardian(s), student, and school staff. Many schools have their own version of a 504 plan and it is perfectly appropriate to use the school's form. However, take care to review it to make sure that it includes the accommodations needed for your child. You can also download an electronic version from the Crohn's and Colitis Foundation here: crohnscolitisfoundation.org/resources/template-section-504-plan.html.

How do I set up a 504 plan?

1. Your parent/guardian will contact the school to set up a 504 plan meeting. You'll usually meet with a guidance counselor or administration before the school year begins, to make sure your accommodations are in place.
2. During the meeting, you'll need to bring a note from your GI team (your MD, NP or social worker) to confirm your IBD diagnosis and request accommodations. You'll discuss:
 - The accommodations that you'd like to set up
 - i. Include anything you think you need for the year, even if you're in remission. If the school tries to remove something because it's not currently necessary, emphasize that IBD symptoms change over time and may become active during the school year, so it should remain in the plan.

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- How the school can provide support
 - What your responsibilities as a student are. (NOTE: Schools are allowed to reject your requests if they are deemed unreasonable).
3. Ensure that all of your teachers are aware of, and understand, the plan. The plan is a shared responsibility.
 4. If your 504 plan isn't providing enough support, your parent/guardian can request an updated plan. Changes can be made to the plan throughout the year at the school's discretion and the parent's request. Open communication with you, your parents and the school. (NOTE: Schools may have requirements that make students ineligible for specific accommodations).
 5. The plan is only good for one year. So, a plan must be created or updated every year even if you've had no changes in your health.

What are some common 504 plan accommodations for IBD patients?

504 accommodations include but aren't limited to the following:

- Unlimited restroom access
- Stop-the-clock testing
- Access to health center
- Exemption from physical education classes
- Flexible attendance for medical causes (arriving late, leaving early/during class, etc.)
- Options to make up missed class time for medical reasons without penalty
- Full participation in extracurricular activities despite classroom absences
- Tutoring following a period of absence due to complications of IBD

Tip: Your needs are unique! The accommodations that work for another student may not be the best fit for you, so think about the specific difficulties you have when planning accommodations.

Do's and don'ts of creating a 504 plan

do's	don'ts
Make sure you are able to identify your needs, and involve your parents for help	Assume your parent is aware of their accommodations
Include how/where/when/why accommodations will be implemented. Be specific.	Assume your school is implementing the 504 plan
Create a 504 plan even if you are healthy at the beginning of the year	Assume every teacher, substitute, coach and administrator is aware of the 504 plan
Make sure the plan is communicated well with the teachers, and check that the current plan is working well	Feel embarrassed creating or having a plan - Know it's okay to get help when you need it

How do I get accommodations if I attend a private school?

Because private schools do not utilize government funding, they are not required to offer 504 plans. However, there are still ways to receive accommodations. The process will likely vary depending on the private school, but generally you will need to:

1. Email the nurse, counselor and/or teachers to let them know of your diagnosis.
2. Speak with your counselor and discuss the accommodations that you may need (ex: frequent access to the bathroom, keeping supplies in the nurse's office). To avoid having an urgent need for an accommodation in an unexpected situation, make sure to ask for any accommodations you may need later in the year.
3. The counselor should then notify your teachers of the accommodations you need.
4. Follow up with your counselor yearly to make sure your accommodations are still intact and updated to your needs.

What if the school doesn't agree to my proposed 504 plan?

Assuming your requests are reasonable, the school is legally required to grant your 504 plan. Parents/guardians can request a due process hearing if they disagree with the decision made regarding the school district's decision, and a complaint can be filed with the district's 504 coordinator. See "Notice of Parents and Student Rights" under the Section 504 of the Rehabilitation Act for more information.

for more information

Visit the Crohn's and Colitis Foundation website, crohnscolitisfoundation.org for more information and resources on 504 plans.

college

Transitioning from home to college can be stressful. Planning and preparation can help the transition go smoothly. Here are some high level tips:

Choosing a college:

Ask questions of schools you're interested in before you go so you can choose a college where you can thrive. For example:

- Can you get a private bedroom or bathroom?
- Are there pharmacies nearby?
- What kinds of meal plans and dining options does the school have?
- Can I get excused absences when I am sick?

Once you've decided which college you will attend, talk to the organizations that can help it be more comfortable. These can include student housing, residence life, food services, a disability resource center, etc. If possible, try to meet with them ahead of time.

Once you arrive:

- Meet with disability services first so that you have any paperwork your professors might ask for. Section 504 of the Rehabilitation Act of 1973 also protects students in higher education. Unlike high school, you must seek out services and advocate on for yourself. Students must voluntarily disclose that they have IBD, provide documentation, and request support or accommodations you need. Share this with disability services, and with your professors.
- When classes start, talk to your professors about your disease. They can help work with you to meet your needs.
- Meet the doctors and nurses in your health clinic.
- Learn where the bathrooms are near your classes and in your dorm.
- Buy snacks that you can eat if you're not feeling well or if you can't find a lot of options at school.
- Once you feel comfortable, talk to your roommate and friends about IBD.
- Pay attention to how you're feeling, and know when you need rest.

Most of all, enjoy it! College is a great time to learn more about yourself, meet lots of new people and have fun, new experiences. With the right preparation, you can be happy and successful in college.

for more information:

Crohn's and Colitis Foundation has a great section on navigating college with IBD. To view those resources, go to crohnscolitisfoundation.org/campus-connection.

work

Just like college, being prepared and communicating about IBD can help you feel more comfortable at work. It is always your choice who and when you share about your disease with. Once comfortable, share with your employer any needs that you may have. For example, if your symptoms are worse in the morning, let your boss know that you may be in late for that reason.

Work stress is hard to avoid, so know what you can do to make you feel more relaxed. That could be taking a walk around the block, listening to a calming playlist or taking a quick break to chat with friends.

As always, getting a good night's sleep, eating well and exercising can all help you take care of yourself and feel your best.

travel

Before you leave for any trip, make sure you're prepared to care for any symptoms while you're away. Here are some tips to help you plan ahead of time:

- Bring enough medication to last through your trip.
- Always carry your medication with you on the plane, and keep it in its original container.
- Ask your doctor for a written plan of action in case your condition worsens while you're traveling.
- Know where restrooms are. Find out in advance whether your transportation vehicles have toilets. Request an aisle seat on a plane.

- Keep your doctor’s phone number and your insurance card in your wallet.
- Always travel with your own toilet paper, soothing wipes, ointments and changes of underwear and clothes.
- Know danger signals, and call your doctor if you experience:
 - High fever and shaking chills
 - Profuse bloody diarrhea
 - Severe stomach pain and/or distension (expansion)
 - Dizziness on standing up, or fainting
 - Scanty, concentrated urine

If you’re traveling internationally, there are more things to consider:

- Learn the lingo: Know how to say “toilet” or “bathroom,” “emergency” or “urgent,” and “pharmacy” and “doctor” in the local language. Downloading an app or getting a book that can help you translate is also a good idea.
- Ask your health insurance carrier whether your policy covers foreign travel. Look into international medical insurance too.
- Avoid traveler’s diarrhea by not drinking the water or ice, eating cooked fruits and vegetables or ones that you peel yourself, avoiding uncooked dairy products, and being careful not to swallow the water when swimming or showering.
- Find a doctor. The American Embassy or the International Association for Medical Assistance to Travelers have lists of doctors in other countries.

