

Guidelines for School/College

What You Should Expect From Us

- To talk to you and listen to your opinions and concerns regarding school or college.
- To check in with school issues such as taking your medicines at school or college, bathroom accommodations, etc.

What We Expect From You

- Open and honest communication about difficulties at school or college.
- To let us know if you are having difficulties dealing with your IBD.
- Communicate with school or college administration about your IBD condition and special accommodations needed.
- Create a 504 plan with school officials and teachers.
- Ask questions – there are no wrong questions, and it's good to have lots of questions.

Why This is Important

Remember it is your decision about who you let know about your child's disease. In situations such as school or college, even if you do not want any special arrangements made for your child, it may help to decrease your stress and that of your child to know that options are available. School is another area of your life that will require planning ahead and organization, your two best allies when dealing with the stress of IBD.

- Make sure the nurse's office is informed of all medications your child takes or any other treatment plan.
- Make sure your child knows that the nurse's office is a safe place to go if he/she is having any discomfort or symptoms, even if it is just to lay down for a few minutes.
- Inform the school if there needs to be any special provisions for field trips, classroom or during testing.
- Consider asking your school to put together a 504 plan, which allow for special accommodations for your child dealing with IBD (which is considered a disability under the law).

Intermittent medical/hospital homebound services vs 504 plan vs IEP plan

- Intermittent or hospital homebound services
 - Academic services to be received at home or at the hospital
 - Must be discussed with your doctor
 - Required paperwork to be submitted by the doctors to the school
 - Academic services need to be approved by the school or school district

- 504 Plan
 - Provides accommodation to your child while at school (see sample below).
 - IBD is a chronic condition and considered to be a disability under federal law.
 - All that is necessary to request the school for a 504 plan is documentation of diagnosis to obtain appropriate forms.
- IEP Plan – Individualized Educational Plan
 - Provides accommodations for children with special educational needs while at school.
 - The chronic condition of IBD exclusively does not qualify a child for an IEP Plan. Other disabilities need to be evident.
 - If your child has an IEP, it can be added to include the IBD diagnosis and treatment plan.

When Meeting for a 504 plan, come prepared to discuss:

- Facts about the disease. What is IBD?
- That the number one goal is to keep the child in school.
- Factors that can make the disease worse.
- Possible urgent need to use the restroom or “bathroom pass”.
- Discuss the closest or most private bathroom to use.
- Nutritional therapy or dietary modifications might be necessary.
- Medication effects or dosing during school.
- Ways to minimize embarrassment surrounding symptoms or medication such as private bathroom or bathroom pass.
- Absence policies or other school accommodations.
- Notify parents if any infectious disease breaks out at the school because your child is at a greater risk due to IBD or immune-suppressant medication.
- Let the school staffs know that you will communicate with them if your child is experiencing symptoms.
- Determine an action plan for the child to safely interrupt the teacher if he doesn't feel well or symptoms arise.

Helpful Tips for College

- When evaluating colleges, it is important to investigate the availability and quality of disability services, school health program and the dining options.
- Check in with the disability resource office at your college and provide a letter from your doctor about your IBD. This office will serve as the liaison between your needs and the college, with regards to faculty and housing. Consider carefully if you need special housing, i.e. a single room or bathroom (in case of needing more rest than anticipated or flare). Upon your request, they will contact

professors to let them know of your classroom needs: sitting close to the door, having extra time to take a test, etc. They will also verify any special housing requirements.

- Check out the dining hall services. Are there foods that meet your dietary needs? If not, work with your parents and doctor to contact the dining department and/or the disability department, it's their job to meet the needs of the students. Keep quick snacks in your room. A mini-refrigerator comes in handy!
- Schedule a course load that will be manageable and not overwhelming. IF mornings are tough for you, plan to take afternoon classes. Find the location of the nearest restroom in each class building and keep spare clothes in the bottom of your backpack.
- Consider telling your resident hall advisor about your IBD. It is his/her job to act as an academic adviser and personal mentor. Your RA might even know about others with IBD.
- Use your college's health center. The center can advocate for you and work to coordinate care with your primary gastroenterologist during times when you need support for a flare or other issues. Most schools require that students complete a medical history form. Be sure to include information from your gastroenterologist, too. Get to know the health center staff and be aware of the hours of operation, cost and insurance procedures.
- Parents, be sure your child is familiar with your health insurance benefits, copays and other important information. If attend a college far away, make sure your insurance will cover out-of-state visits and medications.
- Keep a file of your medical records in case of flare ups.
- Know where the local hospitals, medical clinics and pharmacies are closest to your college.
- Think ahead about scheduling your regular doctor's appointments to coincide with school breaks. If attending a college far away, find a gastroenterologist locally to treat you in case of flare ups. Your primary gastroenterologist can usually assist with finding this doctor. It is better to have a plan and a doctor to call before you actually need one.
- If your child is getting infusions, discuss with your primary gastroenterologist, how infusions will be administered during the school year.
- Take care of yourself! Soon you will be solely responsible for your wellbeing. Get enough sleep and eat foods that are healthy for you. Keep your prescriptions filled and by all means, take your medications! Your parents won't be there to remind you!

SAMPLE 504 PLAN

Developed by Crohn's Colitis Foundation of America

(Your school might have their own form. This sample provides you with information to discuss and accommodation ideas to consider for your own child.)

Section 504 Plan for _____

School _____

School Year _____

Nature of the Disability

This student has a form of Inflammatory Bowel Disease ("IBD") called _____ (Crohn's disease or ulcerative colitis). IBD is a chronic disease affecting the intestines. Ulcerative colitis affects the colon; Crohn's disease can affect any part of the digestive track, from the mouth to the anus. The most common symptoms are diarrhea, abdominal and rectal pain and cramping, nausea, vomiting, fatigue, and arthritis-like joint pain. Although its cause is unknown, IBD involves the immune system and causes inflammation and ulceration of the lining of the intestines. The emotional and physical pieces are interrelated in complex ways, and patients can experience flare-ups during times of emotional tension and stress. Changes in cognitive function including compromised attention and concentration, reduced capacity to process information, disruptions in memory and reduced ability to multitask are also manifestations of this disease. Changes in physiological functioning of the gastrointestinal tract characteristic of this disease can be exacerbated during period of environmental and/or psychological stress. The stress in/and of itself does not cause the disease.

Treatments can include immuno-suppressant drugs that render patients more susceptible to illness and intensify reductions in neurocognitive functioning described above. Patients may be on a restricted diet; may need to eat several small meals per day; and most likely will need to take medication during the school day. Some treatments are provided intravenously in the outpatient hospital setting that may cause a student to miss multiple days of school.

Although surgery is avoided to the extent possible, students affected by IBD may require surgery, including surgical revisions of the digestive track, such as ileostomy and colostomy. Such procedures involve a small piece of the intestine (the stoma) being pulled through the skin and a pouch worn outside of the abdomen to collect waste. Other surgical alternatives create a pouch inside the abdomen. Both procedures require students to have access to a bathroom facility to empty their pouches, and to clean themselves as needed.

Students with surgical resections of the intestines may suffer from the lack of a normal length of intestine, especially when part of the small intestine has been removed. These students may suffer particularly bad diarrhea and altered bowel demands, again necessitating easy access to the bathroom.

Students with IBD tend to be over-achievers or "type-A" personalities and work extremely hard to compensate for their illness and its effects on daily functioning. Students with active IBD will need to use the bathroom several times a day –

sometimes as many as 20 – often on a moment’s notice in order to avoid fecal incontinence.

Incontinence still may occur, and students who suffer this symptom will need to be able to clean themselves and change clothes during the school day. IBD is a chronic illness that is cyclical; patients can face associated gastrointestinal symptoms in a recurrent pattern, with periods of symptom inactivity in between active flare-ups and complications. Symptoms may worsen in an unpredictable manner and conversely, may go into remission for varying lengths of time. Medications can help manage the discomfort and inflammation, but are not cures for IBD.

Introduction to the Plan

This is a Plan developed under Section 504 of the Rehabilitation Act of 1973 (“Section 504”), the Americans with Disabilities Act (“ADA”), and the Individuals with Disabilities Education Act (“IDEA”) to identify the health care-related needs of the student, as well as services and accommodations to be provided to the student.

_____ shall be the point person at the school for purposes of carrying out the provisions of this Plan. This person shall be known as the Plan Coordinator. The Plan Coordinator will educate him/herself about the nature of IBD, the treatments the student is receiving, the side-effects of the treatments, and the student’s particular symptoms and needs. In addition, the Plan Coordinator shall be responsible for ensuring that the provisions of this Plan are carried out and he/she shall be the liaison between the student, his/her family and the school personnel.

For purposes of this Plan, _____ (the student) is a person with a disability under Section 504 and the ADA. He/she is significantly impaired in performance of the major life activity of disposing of bodily waste.

The purpose of this Plan is to maintain the student’s optimal participation in his/her academic curriculum and educational goals, aid in the management of his/her illness, and reduce the student’s stress. This Plan overrides any written or verbal policies established in this School District that may conflict with the Plan in any way.

Any and all communications pursuant to this Plan shall be in writing. Email and facsimile shall be accepted forms of written communication.

The Plan Coordinator and Due Process Rights

The Plan Coordinator shall provide each of the student’s teachers, including substitute teachers, with a copy of this Plan, and shall instruct them to comply with the terms of this Plan.

If the Plan Coordinator is unable to obtain compliance with this Plan by any teacher or other school personnel, he or she shall notify the School Principal immediately, and shall recommend an action plan, including but not limited to discipline of non-compliant teachers if necessary. School Principal shall respond to each such communication from the Plan Coordinator within one (1) school day, and shall accept the Plan Coordinator’s recommended action plan unless there is good cause for declining to do so. “Good cause” shall not include fiscal considerations.

If the School Principal declines to adopt any element or portion of the recommended action plan, he or she shall put his or her reasons in writing within one (1) school day of receipt of the recommended action plan, and this writing shall be sent to the parent(s) or

legal guardian and the Plan Coordinator. In addition, the School Principal shall provide a copy of both this Plan and the writing referred to in this paragraph to an official of the School District who, at minimum, has authority to institute corrective measures on the District's behalf.

Both the parent(s) or legal guardian and the Plan Coordinator shall have the authority to request a due process hearing if the School Principal declines to accept the Plan Coordinator's action plan. This hearing shall be presided over by three members of the School District who are not in any way subordinate to the School Principal or Plan Coordinator. This hearing shall be in addition to, not instead of, any due process rights students and their parent(s) or legal guardians have under the ADA, Section 504, and/or the IDEA.

The Student's Symptoms and Needs

_____ (the student) has the following symptoms and needs, which may change over time:

- _____ Diarrhea (estimated ___ bathroom trips per day)
- _____ Pain and cramping (rated a ___ out of 10, with 10 being the worst)
- _____ Fatigue
- _____ Nausea
- _____ Vomiting (estimated ___ times per day)
- _____ Student has had surgery (___ times)
- _____ Student has an ostomy or other surgical revision of the digestive track
- _____ Student takes medication during the school day
- _____ Other: _____
- _____ Other: _____

List medications and dosages here:

_____ Student has dietary restrictions

Explain here: _____

_____ Student receives treatments/office visits that require absences from school

Frequency: every _____ weeks

Expected duration of absence: _____ days per treatment

_____ Student requires school staff assistance with:

_____ medication

_____ dietary needs

_____ ostomy or other pouch emptying and cleaning

_____ Other (specify): _____

_____ Student needs to maintain a change of clothing at school and may need privacy to clean him/herself and change clothes

_____ Side effects of student's particular medications may cause/impact:

_____ Headaches

_____ Difficulty focusing, concentrating, sustaining attention

_____ Hand/Limb tingling or tremors

_____ Other (specify): _____

_____ Other (explain): _____

Accommodations (select as necessary)

1. The student will be provided with a written "any time" bathroom pass and shall be permitted to use the bathroom, without accompaniment by either school personnel or a student "buddy," at any time, without asking permission, and without penalty.
2. The Plan Coordinator shall walk the student through the school at the inception of this Plan to identify which bathroom facility the student will use when in each class. If a student bathroom is not immediately available, the Plan Coordinator will identify a bathroom closest to the door of the classroom, or a more private bathroom if available, such as in the nurse's office or a staff bathroom. This will help to reduce anticipatory anxiety during times of active flare-ups related to the socially embarrassing nature of some of the IBD symptoms. If school bathrooms are locked for security reasons, the student will have access to a key to other bathrooms closer to the student's classroom.
3. The school nurse will provide the student with a place to lie down if necessary during the school day. Children will be allowed to store a change of clothing in the nurse's office.
4. The student will be permitted to carry a small bag or knapsack throughout the day, which may be subject to inspection, for immediate access to sanitary products to clean him/herself, snacks, a change of clothing, medication (if the student is self-administering medication), and other items necessitated by IBD.
5. The student will be permitted to carry and drink water, eat small meals, candy (to treat dry mouth), or snacks throughout the day in or out of class, as the student deems necessary or appropriate.
6. The student will be permitted to administer his/her own medications in school. If for medical reasons the student is not permitted to administer his/her own medications, the medications will be left with the school nurse, who will administer them to the student at times consistent with prescribing instructions. If the school nurse requires training in administration of the student's medication, the Plan Coordinator shall ensure that the school nurse receives such training within ten business days of the date of this Plan.

7. There will be “stop the clock testing.” “Stop the clock testing” means that, when the student is taking an exam, if he/she needs a bathroom break or a break due to pain, the time for completing the test will be extended by the amount of time the student spends away from the testing room. This accommodation shall be provided without penalty, and shall apply to all tests including but not limited to State Standardized Testing and course exams.
8. If, because of his/her IBD symptoms or medical treatments, the student is unable to take an exam or submit a major project on a given day, the exam or major project deadline will be rescheduled. Cumulative term grades will not be determined until the student has had opportunity to take the make-up exam or complete the major project. This accommodation shall be provided without penalty, and shall apply to State Standardized Testing as well as course exams, term papers and projects.
9. The student shall not be required to take more than one major test per day. The Plan Coordinator will be advised of all planned exams by the student’s teachers. If an exam needs to be rescheduled, the Plan Coordinator will make the necessary arrangement with the teachers. Brief quizzes may be given without prior notice to the Plan Coordinator. A “brief quiz” shall be defined as a quiz that will take thirty (30) minutes or less to complete. “Stop the clock testing” will apply to all brief quizzes. This accommodation shall be provided without penalty, and shall apply to State Standardized Testing as well as course exams.
10. Only one major project shall be due on any given date. The Plan Coordinator will be advised by the student’s teachers of all planned major projects. If a major project needs to be rescheduled, the Plan Coordinator will make the necessary arrangement with the teachers. “Major projects” are defined as those that are assigned more than one week before they are due. If the student is unable to meet a deadline on any project due to anything related to his/her IBD symptoms and treatment requirements, the project deadline will be rescheduled. This accommodation shall be provided without penalty.
11. The student will be given assistance to help him/her make up any classroom time missed due to the student’s IBD, as set forth below. If the student is absent from school for more than one day, or if the absence is planned, the student’s parent(s) or legal guardian shall notify the Plan Coordinator. The Plan Coordinator shall ensure that
 - (a) each teacher provide the student with an updated syllabus, lesson plans, copies of all visual aids, and written homework assignments within 48 hours of when they were presented to the class so that the student can keep up with reading and some school work while absent;
 - (b) each teacher shall ensure that a note-taker in each class who is acceptable to the student will take notes for the student when he/she is absent, and that note taker has permission to photocopy notes on days when the student is absent, or on days when the student is present, but unable to take notes due to difficulty concentrating or writing, or when the student is out of the classroom to take care of medical or bathroom needs;

- (c) on his/her return to school, the student shall meet with the Plan Coordinator, who will assist him/her to schedule make-up tests and assignments; and
 - (d) assist the student to prioritize the work that was missed due to absence. The Plan Coordinator shall make arrangements to ensure that all written materials, including homework assignments, class notes, syllabi, lesson plans, and visual aids are obtained by the student each day, either by providing them to the parent(s) or legal guardian to be picked up, sending them home with a sibling or neighbor who attends the same school, or other method assured to result in daily delivery of the written materials mentioned above. Any and all make-up work shall be designed to show the student's competence in the subject area; quality rather than quantity of the make-up work shall be emphasized. A teacher shall have the right to waive, modify, substitute or amend assignments so as to facilitate the student's ability to catch up on missed work. This accommodation shall be provided without penalty.
12. If the student is absent from school for an extended period of time (i.e., more than 7 consecutive school days), the Plan Coordinator shall determine whether the student is physically well enough to receive in-home or hospital tutoring. If he/she is physically well enough, such in-home or hospital tutoring shall be provided at the school's expense, beginning within 48 hours of the determination that such tutoring is appropriate, in the subjects that the student is currently studying, by tutors who are knowledgeable in the subjects that the student is currently studying. If in-home tutoring is not appropriate, or if the absence is for fewer than 7 consecutive school days, upon the student's or parent's or legal guardian's request, the Plan Coordinator shall determine whether the student requires extra help to make up missed work and, if so, shall coordinate with the teacher(s) to ensure that in-school tutoring is provided as necessary. If in-home or hospital tutoring is appropriate, the school shall provide a sufficient number of hours a day of tutoring so as to keep the student current in his/her classes and assignments. Teachers shall accept any and all work performed under the supervision of a tutor as if it were done at the teacher's instruction. Work performed under the supervision of the tutor shall be designed to keep the student current in his or her assignments. Any and all assignments shall be designed to show the student's competence in the subject area; quality rather than quantity of the work shall be emphasized. This accommodation shall be provided without penalty.
13. The student will not be penalized for tardiness or absences required for medical appointments and/or illness. If the school gives an award for perfect attendance, the student will remain eligible for that award if his/her only absences are due to medical appointments and/or treatment. If the student is tardy, he/she will be permitted to participate in school for that portion of the day for which he/she is in attendance.
14. The student will be permitted to have and store extra sets of relevant books at home or on various levels of the school, so the student does not need to carry heavy books back and forth, or around to all classes for the length of the school

day. This may be relevant if disease activity impacts bone density, or the student's weight or causes fatigue. Where available, the student will be permitted to use school's elevator to get to classes held on various levels of the school in a timely fashion.

15. The student will be permitted to participate in all field trips and extracurricular activities without restriction and with all accommodations and modifications set forth in this Plan. When outside of the school building, the supervising school personnel will identify for the student the location of bathroom facilities. A parent or legal guardian or someone designated by the parent or legal guardian may drive the student to the field trip or extracurricular activity location if it takes more than a half-hour to arrive at the location so that the student can stop for bathroom breaks.
16. The student should be permitted to self-monitor his/her energy level and fatigue during gym class to determine if he/she feels capable of participating in a given physical education unit. If there is ongoing non-participation in gym class due to fatigue or other physical symptoms, the physical education teacher shall notify the Plan Coordinator, who shall notify the student and his/her parent(s) or legal guardian. The Plan Coordinator shall inform the student and parent(s) or legal guardian, who shall be responsible for seeking medical care, and medical verification of contraindication of physical exertion. This accommodation shall be provided without penalty.
17. The student will be encouraged to engage fully in all school activities, and will not be discouraged from taking medication on time, eating snacks on time, complying with all dietary restrictions, taking bathroom breaks, or any of the other accommodations set forth above. All of the provisions of this Plan shall be provided without penalty to the student.
18. Alternate seating must be available to the student for easy access to the classroom door to facilitate bathroom breaks and reduce anticipatory anxiety. The student may alter location in classroom seating charts, as well, if a neighboring student has or appears to have a communicable illness.
19. The school shall notify the student or his/her parent(s) or legal guardian of an outbreak of chicken pox or other infectious disease as to which the student is at a greater risk due either to IBD or immuno-suppressant medication.
20. The student shall be permitted to carry a cellular telephone, and be allowed to use it in an emergency that precludes the student from reaching a school telephone to contact his or her parent(s) or legal guardian.
21. Any teacher or other school personnel having questions about this Plan shall raise those questions with the Plan Coordinator. If the Plan Coordinator believes that there are concerns that are not addressed in this Plan, the Plan Coordinator shall notify the parent(s) or legal guardian and schedule a meeting that shall include the parent(s) or legal guardian and the student.
22. Academic accommodations necessitated by changes in cognitive functioning due to IBD symptoms/diagnosis must be addressed and considered separately on a case-by-case basis.

Emergency Contacts

In case of a medical emergency, school personnel will notify the Plan Coordinator, who will call _____ at the following telephone number(s):

Home: _____

Work: _____

Cell: _____

Other: _____

Signed:

Parent or Legal Guardian Plan Coordinator

Student (if able to understand considerations)

Principal

School Nurse