

TAKING IBD TO SCHOOL

The pressures that all students feel at the start of the school year are greatly magnified when IBD is part of the curriculum. Kids with Crohn's or colitis face additional challenges: How will their disease affect their grades? Their relationships with teachers and classmates? Education and communication can ease these concerns.



ATTENDING ELEMENTARY THROUGH HIGH SCHOOL

For students below college age, the most important factor is ensuring that their teachers and school administrators have adequate information about their disease.

"It can be difficult to communicate effectively with all of your child's teachers in middle school or high school," says Diane Ketlak, M.A. School Psychologist, W.S. Parker Middle School, Reading, MA. "First, contact the school nurse, guidance counselor, school psychologist, special education coordinator, or principal. These people can play a significant role in coordinating information to all staff who have contact with your child."

Every faculty person doesn't have to know every detail, but every individual

the students will come in contact with does need to know what the students should be allowed to do to accommodate their disease. "You never know if there will be a substitute teacher or classes will be combined. In those cases, IBD students won't necessarily want to go up and describe their symptoms," explained Karen Herlihy, a pre-K/elementary school teacher at Rosary Academy Learning Center in Watertown, MA, who has Crohn's disease herself.

Jane and David Wolfman from Lexington, MA, whose 12-year-old daughter, Julie, has Crohn's disease, told her teachers in advance that she'd be absent from school at times and asked how to handle the situation. "It worked out fine. I always knew what they needed me to do and they always knew what we needed them to do. And Julie knew she wouldn't fall behind," Jane reports.

Don't be afraid to ask for a team meeting so you can speak directly to all of your child's teachers and support staff. They will often have prior experiences with chronically ill children and may offer advice that can be very helpful and reassuring.

You can also distribute literature about your child's illness and treatment at a team conference. "When Julie was first diagnosed, we found the printed materials from CCFA to be outstanding, especially the brochure on explaining Crohn's to your teacher. We downloaded it, copied it and gave it to every teacher. And the teachers were so appreciative," says David. "There's a huge difference between reading a note from the principal saying a child is sick and reading CCFA guides and really understanding the disease," Karen adds.

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Parents may sometimes need to work behind the scenes to moderate the amount of stress their children take on without defeating their will. “Students with chronic illness often work extremely hard to over-compensate for their illness and try to maintain an unusual amount of control,” Ms. Ketlak explains. “It can be very helpful for a teacher to know that a youngster is having a tough day or feeling particularly stressed. The teacher can then extend the deadline on a project or allow a makeup test in a natural manner without drawing attention to the situation.” Teachers and school staff are acutely aware when situations should be kept confidential and will honor such requests.

Students should communicate with their teachers, too. “It really helps you through the school time if you find just one teacher that you can really trust. If you keep it to yourself when you’re not feeling well, it’s going to take you much longer to recover,” says Karen. “When you go to your teachers, you’ll see a different side of them, the personal side,” adds Alison Rosenfeld, a 17-year-old high school student from Newton, MA who has Crohn’s disease. “They can be very compassionate. And they see the other side of you, too.”

This happens more easily when the students are open and well-informed about their disease. “The best way to relieve their stress levels is to ensure their self-esteem is high and that they’re comfortable with being an IBD patient,” David Wolfman says.

David’s daughter, Julie, and Ali Rosenfeld are very open with their classmates as well as their teachers. Both have given class presentations about their disease. “It helped me to tell people what I was going through, because if you keep it inside and don’t give other students and adults that chance to possibly give you the

support you need, you never know if you’re going to get it,” explains Ali.

Adolescents can be reluctant to share information about their medical condition. They may need to be reminded that facts about their illness are less frightening to their classmates than rumors. The more the other students know, the less likely they will be to alienate or tease them.

If they are teased or harassed, Ms. Ketlak suggests role-playing at home or using humor to disarm the teaser. “While some cases may require intervention by a parent, this can sometimes backfire, reinforcing a child into becoming a victim.”

If your child’s needs are not being met despite your and his/her best efforts, remember that Federal law requires public schools to provide chronically ill students with a free and appropriate education in the least restrictive environment. “Schools should evaluate a child’s special needs and develop a plan, which is known as an individualized educational plan (IEP), for satisfying any medical requirements. Parents may rightfully expect these plans to be developed and enacted. If they believe that their child’s rights are not being protected, they may appeal to the courts,” says Ms. Ketlak.

GOING OFF TO COLLEGE

Danielle Karr, a senior at Brown University who’s majoring in computer science economics, was diagnosed with ulcerative colitis when she was a senior in high school. Since she had already completed her college applications, it was too late to investigate how the schools could accommodate her disease. “I just sort of showed up and went with it,” she says. To spare

other students from having to learn things the hard way, she offers the following advice: “Find a school that’s right for you and then worry about the details of your health care. There are ways to fix just about any problem with a little effort on your part.”

Danielle cautions that if you’re unhappy with your choice of school, your health and studies will suffer. IBD doesn’t necessarily preclude study abroad programs either. Most developed countries have gastroenterologists that can consult with your doctor at home if the need arises. In addition, many of these countries have patient organizations, such as the European Federation of Crohn’s and Colitis Associations (EFCCA). To locate an association in a particular country, check out “International Organizations/Information in Other Languages” at: www.ccfa.org/research/links.

“As soon as you pick your school, file with Disability Support Services (or your school’s equivalent) to make sure your housing comes with a closely located bathroom. Deadlines are really early,” she warns.

“If you’re too far away from home to commute for check-ups, work with your regular gastroenterologist to find another doctor near school. Talk about what you should do in the event of a flare-up while you’re at college: Should you first call your doctor, make a doctor’s appointment or go to Health Services? Be sure to give your doctor the phone and fax numbers for Health Services in case he or she needs to speak with the staff or order a test for you.”

Before heading off to college, Danielle also recommends finding out what services (lab, pharmacy, X-ray facilities, etc.) the clinic at school provides and telling your doctor about them when you’re developing your contingency

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plans. “If these services aren’t available on campus, see how far you have to go to get them at a hospital or clinic.”

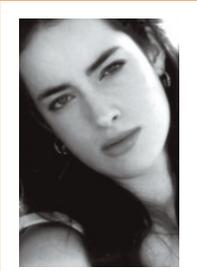
“If you take maintenance medications, determine ahead of time where you can fill your prescriptions,” she says. Bring at least a month’s supply of pills with you, along with the name and number of your old pharmacy, so

that you can easily transfer your remaining refills.

Once you arrive on campus, familiarize the school physicians and health personnel with your case. The health clinic should also be apprised of any changes in your health during your time at school. And while you’re learning your way around campus,

note the locations of bathroom facilities and find out when they’re open.

Schedule an initial appointment with the gastroenterologist in your college town as soon as possible. This doctor should know your complete history with IBD, your medications, and the results of your most recent tests. He or she should not make any major



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decisions, such as changing your medication or restricting your diet, without consulting with your primary doctor back home. That physician is more familiar with your individual situation and can make the best decisions regarding your health.

If you have many diet triggers that limit what you can eat, Danielle

suggests talking to both your doctor and the dining services nutritionist. "The nutritionist can fill you in on the type of menus at dining halls and the other options available all the time, like grilled chicken, salad bars, and pasta, that often don't even make it on the menu."

Students receiving nutritional supplements may find a nutritional support service in town or at a local hospital with the help of their doctors. The doctor can suggest a routine that will allow the necessary caloric intake while interfering as little as possible with academic and social life.

Ingesting other substances is a temptation that students with IBD had best avoid. "We face not only the normal risks of hangovers and alcohol poisoning, but also have to think about how alcohol will mix with medications and whether it could trip a flare," Danielle explains. She recommends talking to your doctor (without your parents around, if that's more comfortable) about the potential repercussions. "Keep in mind that in recent studies, 72 percent of college students characterized themselves as occasional or light drinkers or abstain entirely. So if you determine that you don't feel the need to drink, you won't be alone." Of course, the same caution applies to drugs, but the potential damages are even greater.

Who else do you need to discuss your medical condition with? Only who you want to. "I tell the people who can help me or that I live with or who I'm really close to," says Danielle. "If you want to be an advocate or let a lot of people know about your situation to raise awareness, that's fine. But when you go away to college, chances are, you don't know that many people. You have an opportunity to make a brand new you. You are as you are for whatever reason, and there's no need to explain that to anybody."

Danielle will be happy to answer questions from and about college students with IBD. Her email address is Danielle_Karr@brown.edu ■

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