

# A great education—with MS



## **A spectrum of strategies can help people with MS achieve their educational goals.**

by Kelly Smith

Pursuing an education is a time-honored way to better oneself, and multiple sclerosis should not stand in the way of that goal. Know the legal rights of students with MS, take advantage of available resources and pay attention to the lessons learned by others. In this story, **Momentum** follows four students through their journey to obtain the best education:



### **Channing Barker**

Now in her early 20s, **Channing Barker** was diagnosed with MS in 2006 during her junior year of high school in Fayetteville, Ark. “Somebody told me that your energy is like a storage bank—you only have so much. You have to spend it wisely,” she says.



### **Kathleen and Claire Flaherty**

**Kathleen Flaherty's** daughter Claire was diagnosed with MS in 2007 at age 7. Her first exacerbation resulted in a long hospitalization and required extensive rehabilitation. The family engaged tutors to help Claire catch up in school, and she now follows a full-day schedule. "You are the advocate for your child," Kathleen says. "Only you can tell school staff what she needs."



### **Emily Blosberg**

**Emily Blosberg** was diagnosed in 2011 while in eighth grade. Her father Dean was diagnosed in 1998. "My wife and I are concerned about college and what kind of struggles Emily may have. We're learning all the available options before she goes," says Dean, of Shoreview, Minn.



## **Reyne Mullins**

**Reyne Mullins** was diagnosed with MS in 2009 during his junior year of high school. He was a National MS Society Top Scholar and is now at Earlham College in Richmond, Ind. He recalls how much his teachers cared. “Some kids shut teachers out. They feel ashamed to talk about their MS or think teachers don’t want to hear about it, but that may not be true,” he says.

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## **A is for advocacy**

Whether you’re a student with MS, or the parent or child of a student with MS, it’s important to know how MS symptoms can affect education—and the best strategies for managing them. One strategy, however, cuts across all levels of education, from kindergarten to college: self-advocacy.

## **Survey results**

[“What is your biggest educational challenge?”](#)

In a nutshell, self-advocacy means speaking up for yourself to get your needs met. “I learned to talk to my teachers and tell them what I had going on,” says Channing Barker, who was diagnosed with MS in 2006. “I also worked with the disability office at my school, the University of Arkansas,” she relates. “It’s about standing up for what this disease does to you.”

“At the beginning of every year, I meet with all of Claire’s teachers,” says Kathleen Flaherty,

whose daughter Claire was diagnosed with MS in 2007. Kathleen gives each teacher a copy of the Society's handbook, *Students with MS & the Academic Setting: A Handbook for School Personnel*. "I explain what MS is, and tell them about Claire's medical and cognitive issues."

## Learning the law

Kathleen recommends that parents learn all they can about the full range of legal protections their children have. "The standard line I get all the time, even from medical professionals, is, 'We didn't realize kids could get MS,'" she says. That means she has to raise awareness across the board—from confirming that, yes, children do get MS, to how symptoms may affect school performance.



Meet Claire Flaherty



A mother and advocate



In the classroom



Finding friends who care



Working with teachers



A favorite subject

Any student with physical, cognitive or other disabilities is protected by federal laws, including the Americans with Disabilities Act, which prohibits discrimination on the basis of disability, and Section 504 of the Rehabilitation Act of 1973, which protects the rights of individuals with disabilities in programs that receive federal funding from the U.S. Department of Education.

Section 504 contains the Individuals with Disabilities Education Act (IDEA), which ensures that

every child with a disability is entitled to a “free and appropriate public education.”

Under IDEA, school districts must establish standards and procedures to evaluate and appropriately place students who need special education or services and aids. The school district must then develop a documented plan, such as an Individualized Education Program (IEP), to provide what the student needs to fully access a learning environment.

## **College and the law**

“It’s important that the child have documentation of a 504 Plan or IEP before they finish high school; otherwise it will be extremely difficult to get the right services in college,” says Laurie Lou Smith, EdS, a nationally certified school psychologist who works with the Center for Pediatric Onset Demyelinating Disease in the Department of Pediatrics at the University of Alabama in Birmingham.

## **Financial aid**

Learn about the [National Multiple Sclerosis Society’s scholarship program and other financial aid](#).

Once at college, Smith recommends that the student contact the college’s office of disability services to request accommodations. She says it’s best to visit the office in person, which will help develop an ongoing relationship.

Reyne Mullins learned this firsthand. After a tough first semester, he visited his college’s office of disability services, which now provides him with test accommodation slips each semester. The slips detail his need for a private testing room and twice the allotted time for testing. He was also able to move into a single dorm room, where he could rest any time of day. While schools may be required by law to identify students with disabilities and provide what they need for an equal education, that doesn’t mean they will capture every turn of a complicated and unpredictable disease like MS. There’s a whole range of accommodations that schools could offer that they’re not necessarily obliged to provide by law.

Therefore, it’s essential for students and their families to identify symptoms that affect attendance, studying and participation, and to stay aware of how symptoms may change over time. A frank discussion with a neurologist is a good place to start. Your doctor can also provide referrals to other healthcare providers, such as physical or speech therapists.

## **Ways to manage**

Emily Blosberg has permission to wear a baseball cap or sunglasses in the classroom, due to vision difficulties created by artificial lighting. She also has a volunteer reading buddy because even five to 10 minutes of reading can give her headaches and fatigue. She

downloads free audio textbooks from the Library of Congress, and utilizes [Learning Ally](#), which offers audio textbooks for a small charge. “I don’t take a full class load. Instead, I have an hour break during the day after lunch,” she says. “It helps me get through the rest of the day.” She has taken several independent study classes and plans to do the same in college.

Claire, too, has made special arrangements to accommodate her visual challenges. She receives textbooks and handouts with large print. She also keeps an extra set of textbooks at home so she doesn’t have to carry them to school each day. She has an easier-to-see combination lock for her locker—one with a sliding lever rather than a traditional circular lock. Her mom purchased it for her after realizing she had been asking a friend to open her locker for an entire semester. During elementary school, the school provided a portable air conditioning unit to help her remain cool, as her classrooms were smaller and got hotter than they do now in her high school.

## **Your best on the test**

## **Learn more**

The Society offers several education-related brochures for students, parents and school staff, including:

- [Your Education Rights as a Student with MS](#)
- [Managing School-Related Issues: A Guide for Parents \(PDF\)](#)
- [Students with MS & the Academic Setting: A Handbook for School Personnel \(PDF\)](#)
- [A list of strategies for parents and children with MS](#)

Learn more about IDEA, or the Individuals with Disabilities Education Act, at [idea.ed.gov](http://idea.ed.gov), and the Americans with Disabilities Act at [ada.gov](http://ada.gov). and [disability.gov](http://disability.gov).

Test-taking, especially timed, standardized tests, can be a big stressor for students with MS. But students and parents can work with schools to find ways to help students with MS achieve their best results. Barker worked with her high school counselor to receive time accommodations and a quiet room when taking the ACT. For Emily, too, accommodations help at test time. She receives tests in large-font format and has no time limit.

Extracurricular activities are often valuable additions to college applications. But as areas that, for the most part, fall outside the realm of Section 504, students with MS must choose and manage those activities wisely. For Barker, that meant “managing my stress and my symptoms, taking my meds and learning time management; I gave myself permission to say ‘no.’ ” Unfortunately, sometimes the disease also said no to her. “One of the hardest things for me was that I lost my ability to dance,” she remembers.

For other students with MS, activities may help them build social and teamwork skills. Claire participates in student council and cheerleading and is also a member of her school's track team. "It took me a long time before I felt confident that Claire would be safe in some of the things she wanted to try," says Kathleen. "I realized I wasn't doing her any favors by holding her back."

## **Social needs**

Learning to navigate bias and other social issues is another part of the education process. Claire is pragmatic when speaking about the problems she sometimes encounters with other students. "Sometimes kids are mean," she says, matter-of-factly. "I just ignore them or walk away. I think those kids don't know me or don't understand."

## **Sports and MS**

Learn how exercise can improve function and quality of life in "[The Sport You Choose](#)."

Students who are encountering prejudice against people with disabilities can call an MS Navigator at 1-800-344-4867 for nearby programs and support groups.

Emily was asked to speak during a school assembly, so she spoke about her diagnosis with MS, why she missed so much school, and how she would much prefer to be treated normally rather than pitied or babied. "The feedback she got from students, parents and teachers was that they were grateful to know what was going on; it answered questions for them," her father Dean recalls. "It helped her realize life could change for the better, if she could open up and let them in."

Mullins was hospitalized during high school and received an oversized card signed by his classmates. "I started to get a sense of how many people cared about me," he says. "Now, I pay attention to these circles that I'm involved in. It's in line with advocating for yourself and realizing you are in a position to be valued by others, but also by yourself."

**Kelly Smith is an award-winning editor who lives near Denver with her family.**

Start or join a discussion about MS and education at [MSconnection.org](#).