Off to college—
with MS
by Carrie Bryant

I was diagnosed four years ago, while my identical twin sister, from whom I’d never been separated, was off to college doing what I thought all college kids should be doing. She was staying out late, hanging out with friends, going to parties … oh yes, and studying, of course. I should have been at Middlebury College in Vermont, studying Classics. But I just lay in bed, pumped up with steroids.

For most people, the idea of deconstructing Greek and Latin sentences probably sounds like a nightmare. For me, these knotty sentences were like exciting puzzles. When I solved them, everything made sense and kept my mind off a body I couldn’t control. But could I handle these sentences now?

Moving forward
It was my doctor who got me moving. “You don’t belong at home,” he insisted. “You belong at school.”

I poked around and discovered that Middlebury accepted freshmen in February. My doctor continued to adjust my medications, and five months later, I was finally well enough to leave home, according to my doctor.

During orientation, as I sat with my parents and listened to professors talk about course loads and curriculum, I panicked. I was tired all the time. How could I handle it all?

“I want to go home,” I told my mother.

“You can do it,” she answered. I wasn’t so sure.

Someone on my side
The turning point came when I met my advising professor. My mom and I had decided that she would disclose my MS during the interview. Somehow, I thought it would be OK if she said it; I couldn’t bring myself to. But when she told the professor, I started to cry.

The professor told us his wife and sister had MS, and he knew exactly what I needed. He arranged for a lighter course load, allowing me to make up classes during summer if I wanted to finish in four years. He advised me to get a dorm room on the ground floor.

I started to think I could do this, after all.

Getting the best, skipping the rest
Never wanting to be “the sick one,” I tentatively made friends—only to discover that they had all been through struggles of their own. One had lived through the death of a parent. I was not alone.

These friendships were deeper than what I had experienced before. We shared compassion. And did I mention fun?

I was too tired to attend late-night parties, but we went to restaurants, played basketball, and watched movies. And when I decided that I wanted to raise money for MS, five of my friends formed a committee and helped me organize a Walk MS event on campus. Hundreds attended and we raised $80,000.

Support online
The day of the Walk I met a guy with MS who went to a nearby college. We talked about how we were tired of being the only two people with MS at school.

“Why isn’t there a support
In college or thinking of going?

Worried about juggling exams, working, friendships, and your MS at the same time?

Join the MSWorld College Chat, a great opportunity to connect with people like you. Launched by the Central New England Chapter of the Society, it’s a weekly, co-moderated chat designed specifically for people with MS facing life after high school all across the country.

When? Log on to MSWorld.org Tuesdays at 7:00 PM ET to 8 PM ET, and sign up for a username. Once registered, enter the general chat room, then click on MS College Kids and you’re there!

Group for college kids with this disease?” I wondered. And the idea tugged at me.

Now, two years later, my idea has turned into reality. It’s called the MSWorld College Chat. It takes place every Tuesday night on the MSWorld Web site. I’m one of the peer moderators: Carrie1NS. We give each other support and ideas about how to live with MS. We’re there for each other.

As I meet the challenges of senior year, I’m once again deep

Tips for handling hidden symptoms

by Marcella Durand

It can be tough to get a teacher, or even a parent, to understand MS fatigue when there are chores or homework to be done. It can be hard to tell your friends that you feel too weak to play basketball. You may even feel like two people—one who looks “OK” on the outside, and one who feels awful on the inside.

• Talk to others who have MS
While your friends and family try to imagine what you’re feeling, a person with MS will know exactly what you’re talking about.

“One of my biggest turning points was when my parents made me go to Teen Adventure Camp,” said Nicole, 17. “I didn’t want to go—I didn’t want to talk to others like me. But I realized how much I needed someone who understood.”

• Be an educator
Think of yourself as a teacher. Many people don’t know much about MS, so you’re raising awareness whenever you say something.

Try comparing your symptoms to familiar experiences. “I told my friends how I felt like I just ran 10 miles when I walked up stairs,” said Olivia, 14. “They get it now.”

Nicole explained her optic neuritis to her mom this way. “I told her the vision in my left eye looked like when a person takes a picture with a flash, but the dots won’t go away.”
• Don’t explain if you don’t want to
You don’t have to give a long explanation to everyone all of the time. Sometimes it’s OK to just not be in the mood.
“If my friends ask me to go out and I’m not up to it, I just tell them I’m tired,” Olivia said.

• But do talk to someone
People may mistake your fatigue for laziness or worse. And you may feel alone and depressed if you don’t reach out and express how you’re feeling. Choose who you tell. Besides friends, it may be important that teachers, family, and health-care providers know what you’re going through.

• Ask for backup
Unfortunately, there’s the occasional teacher who doesn’t understand why you need to nap in the nurse’s office. When this happens, don’t hesitate to advocate for yourself—and get backup. Tell your parents and ask them to help. Ask a school counselor, or call the Society, where there is someone who can help educate school staff or provide resources about issues of MS.
“I told my guidance counselor, who set up a meeting with the teacher,” remembered Shimon, 17, when a teacher was misinterpreting his fatigue.

• Choose your friends
“My best friend has been there the entire time,” said Nicole.

Fatigue, numbness, headaches, bladder and bowel issues, weakness, vision problems, pain, balance problems, trouble remembering words: All these symptoms are mostly invisible to others.

“He rode the MS150 last year and we’re starting a nationwide fundraiser.” After she had trouble talking with other friends about her MS, she made new ones.
“I met people I consider true friends—and they are so important to me now.”

For more information about Teen Adventure Camp, visit pediatricmscenter.org. To find events for people your age with MS, call your chapter or visit nationalmssociety.org.
To chat online with other teenagers with MS, visit msworld.org. Or e-mail childhoodms@nmss.org and ask to join Young Persons with MS: A Network for Families with a Child or Teen with MS. It offers an e-mail group especially for teens with MS.

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