Notes from a [Former] Reader



nbelievable," I thought as I hung up the phone. My favorite author, Joyce Carol Oates, was going to be the speaker at our library's annual literary luncheon, and I had just been asked to write the introduction and sit next to her! I was astonished, exhilarated, grateful, proud—but mostly overcome by the irony of it. There I was, invited to meet and talk with my dream author, a writer whose books I have devoured over the past 30 years (I own more than 40 titles)—and I can no longer read, or remember much of it. Ten years ago I could have cited chapter and verse, and now it's all a blur. I just have to shake my head and laugh.

Ten years ago, at the age of 48, I developed multiple sclerosis. At first I experienced double vision, which completely resolved itself in four months. Then a year or so later I had pain, numbness, and tingling in my legs, symptoms that are still with me, though muted somewhat by medication. When I was eventually diagnosed with MS, I didn't cry or feel sorry for myself. I'm a very pragmatic person. When I encounter an obstacle, I don't ask why; I just start thinking of ways to get around it. When I had double vision and couldn't drive. I walked to the stores and asked friends to take my children to school. When my legs hurt, I got a handicapped parking placard. I take a daily 25minute "power nap" to counter my MS fatigue, and every morning I give myself an injection of a drug that slows the

course of the disease. I take vitamins; I drink gallons of water; I'm doing everything right. But gradually I've become aware of a symptom I can't compensate for. This one is much too close to the bone, too entwined with my sense of self.

I was always a voracious reader. In addition to The New York Times and a hefty stack of magazines, every week I read a novel or short-story collection—good literary fiction. My dining room was filled with hundreds of books, arranged in alphabetical order by author and date of publication. It will

come as no surprise that I have a master's degree in library science. Sometimes there was a compulsive element to my reading. I'd get edgy as I neared the end of a book: What if I couldn't get to the library or a bookstore to find something new? I was a reading junkie, always needing another fix.

We moved from New York City to the suburbs a year after the birth of our second child, and I was concerned about finding friends with similar interests. But my apprehensions faded away when I joined the newcomers' book club: Here were women who were smart and funny and read the same books I did. I lived for the monthly meetings and the chance to spend an hourand-a-half talking about ideas instead of children and window treatments. Soon I was chosen to be the group's leader. I spent

a lot of time rereading the selected book, researching the author, finding reviews, thinking of ways to stimulate discussion. The group grew from five or six to about 20—too many to fit in most living rooms—and I felt much of this was due to my visible love of books. I felt most alive and creative in the book club; it truly was a high for me. Then

was a high for me. Ther MS came into my life.

One of the odd aspects of my double vision—and believe me, double vision is defined by odd aspects—was the fact that, for me, things did **not** appear double at very close range. Therefore the most comfortable activity for my eyes and

brain in that state was to read. I continued leading the book club that fall, despite the distraction of trying to discuss Edith Wharton while everyone in the room had two heads.

But after my vision returned to normal, I noticed that I was reading much less than before. My concentration was somehow off. I couldn't describe what was wrong, but I felt that something had changed.

Over the months that followed, I became aware that the hyper-prolific Joyce Carol Oates was literally writing faster than I could keep up with. "Cool it, Joyce," I thought. My book club friends humored me and insisted that my concentration problems were due to approaching menopause, not MS, but it pained me deeply that I had become so slow doing what was once as easy as breathing air.

My sensitive neurologist, an MS specialist, took my vague complaints seriously and referred me to a neuropsychologist for testing. The results confirmed that, compared with other women of my age and educational level, I had suffered cognitive loss consistent with MS. Word retrieval, memory, and concentration

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My doctor prescribed a drug most often used for Alzheimer's patients, but when it gave me amazing night terrors, she suggested Ritalin, which has enabled me, like people with Attention Deficit Disorder, to focus on the bank statement, dinner, or our holiday newsletter for a few hours. Books, even my growing pile of New Yorkers, now have to wait for vacations, when there are no ringing telephones, burning cookies, or children's homework questions to distract me.

Perhaps because of my inability to participate, or maybe just because all our lives have changed, our book club has wound down. We often meet to see a play or museum exhibit, to fool around with clay or beads, or just to talk. But recently

when we met, all the others brought books to share or reviews to pass around. I felt invisible as the others bounced around titles and even authors' names I'd never heard of. It was as if I were wearing a disguise, the cloak of a nonreader, that was getting tighter and tighter, squeezing me. But as I struggled to take it off, I found that it had bonded

with my skin. This is what I am now. I may seem the same in most ways, but in this crucial respect I am a stranger, even—especially—to myself. Who am I if

I am not a reader?

Writing this, I see how frustrated, even angry, I am about this loss. I vividly remember

how terrified I was when I developed double vision. Lying in bed, unable to sleep, I wondered if I were going blind. What would I do if I couldn't read? I frantically thought of alternatives: books on tape, hiring a high school kid to read to me. I thought then that the only thing that could prevent me from reading was a problem with my eyes. I had no inkling of what could happen to my mind.

Then came the request to write the Joyce Carol Oates introduction. To do it I had to chain myself to the dining room table for a couple of weeks. I took pages of notes. In the end, it was very pleasing—and validating—to hear the chairwoman read my words to an audience of 500. As for spending an hour or two next to a writer I had idolized for so many years, well, imagine eating lunch with your hero. I bet you wouldn't clean your plate either.

Ms. Oates was charming at the table, asking a lot of questions about our lives and interests, and she was a fabulous speaker. She truly made art accessible, and the audience was captivated.

This momentous, bittersweet event, so thrilling and yet so frustrating to me, stands as a reminder of my abilities and

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disabilities. Yes, with a great amount of effort I could assimilate information and craft a good, concise introduction. But I could not talk to my favorite author with the assurance of the careful reader I had once been. Yes, I am still close to my book club friends, but I no longer share the passion that brought us together. Yes, I'm a good mother, a caring friend, a cheerful volunteer. Being open about my MS has enabled me to gain the confidence of others. MS has made me more empathic, and for this I am grateful, but I can't stop missing the clever bookworm I used to be.

Maybe now is the time for the tears that did not flow 10 years ago, for I truly have lost a cherished part of myself. ■

Deborah Turner lives with her husband and two children in suburban New Jersey.

Comments from the Clinic

by Valerie Armstrong, ARNP, MSCN, CRRN

Being able to recognize the cognitive changes common in MS is very hard. The problems are often subtle. Almost everyone has experienced doing things like asking for directions while driving, and then having to ask for them again. When do lapses like that become a medical problem?

I suggest a self-checkup. Do you have problems getting tasks finished? Have your hobbies fallen by the way-side because they take more time than they used to? Are memory problems interfering with daily life? Important examples might include forgetting whether you've paid bills until second notices arrive or discovering you've been missing scheduled appointments.

Ms. Turner recognized her problem and faced it bravely. She began by talking with her neurologist. Talking with family members may also offer valuable insight, as their input may help frame what needs to be discussed at a medical appointment.

Resources include nurses and rehab therapists. The process might include referral to a speech-language pathologist, an occupational therapist, a mental health counselor, a licensed social worker, or a neuropsychologist who specializes in the cognitive impact of MS.

There are some options and treatments. For example, one small study found that Aricept, a drug approved for the treatment of memory disorders in Alzheimer's, offered modest benefit for verbal memory problems in MS.

Importantly, cognition is not a stagnant process. It evolves. So re-training may be one of the best approaches. In preparing her talk on Joyce Carol Oates, Ms. Turner eliminated distractions. She took breaks to summarize what she had read. She took notes.

Some people want to know how many pounds they can bench-press at the gym. Only by working out over time can one know. The same principle applies to the mind. Ms. Turner may always grieve for the fluent, analytic reader she once was. The loss is painful. But she may also discover some pleasure in reading in a different way. Using your mind to help your mind is the best defense against MS.

Valerie Armstrong is a nurse practitioner at Mayo Clinic MS Comprehensive Care Center, Jacksonville, Florida.