

My retirement party's salute to MS



Comments from my colleagues about how I handled my disease were unexpected but deeply moving.

by **Kenneth Bandler**



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The terms “multiple sclerosis” and “MS” permeated remarks at a luncheon my longtime employer convened recently. I expected to hear shared memories of accomplishments as I retired from the American Jewish Committee (AJC) after heading the global advocacy organization’s media relations operation for nearly 25 years. I did not expect comments about MS.

Several colleagues saluted how I have dealt with MS as I carried out a multitude of tasks

daily, as well as on weekends, to promote AJC's mission and work. "Ken did not want to be viewed differently, judged differently because he had MS. He did not wear it on his sleeve. Yet, he dealt with it," said David Harris, the former AJC CEO who had hired me and with whom I worked closely for nearly my entire tenure.

Keeping symptoms private

I have long considered my health a personal matter, not to be discussed with an employer unless circumstances compelled me to request a sick day, and, thankfully, that happened rarely. And while I decided 19 years ago to tell Harris that I have MS, rarely was it discussed.

My relapsing-remitting MS was generally stable. To colleagues, as well as others outside AJC I encountered in New York and on business trips across the U.S., Europe and the Middle East, I appeared to be fine. In reality, though, I confronted unexpected bouts of fatigue, sudden symptomatic flareups and other conditions that presented temporary impediments to my job that I overcame each time.

When I arrived at AJC in December 1998, eight and a-half years after I was first diagnosed with MS, my original symptoms, mostly numbness in the feet and hands, had waned.

It had been at least five years since I had seen the neurologist who diagnosed me in April 1990.

It was exhilarating to be at a dynamic, influential nongovernmental agency. I traveled to Belgium, Cyprus, Egypt, France, Germany, Greece, Israel, Italy, Jordan, Mauritania, Oman, Poland, Qatar, Switzerland, and the Vatican.

A turning point

After only five years in the job, my MS changed. Fatigue came more regularly. I was finding it difficult to stay up at night to write or edit as I was accustomed to doing. Numbness that originally had been limited to my feet and hands when I was first diagnosed were spreading up my arms and legs. Even my face sometimes felt profound numbness.

That these sensations were occurring amid meetings in the CEO's office, in conference rooms with senior management or outside guests, or when traveling was unsettling. I initially tried to ignore what I was feeling while pursuing my work. During an appointment in January 2003, my primary care physician asked about my MS and strongly recommended that I see my neurologist again. I realized that what I had been experiencing required more expert attention.

My second MRI, in April 2003, revealed more lesions in my brain. I started going to an MS center in New York City and began taking a disease-modifying therapy (DMT). By the end of that year, I had written an op-ed about my experience with MS, but could not publish it without disclosing my condition at work. It sat on my computer for months. One evening in late May 2004, I told CEO Harris and shared my essay with him. He encouraged me to get it

published.

The day before the op-ed appeared in the International Herald Tribune, in June 2004, I told a few other colleagues with whom I was working closely, as I thought they might see the article.

I didn't share the piece with too many people. I still was ambivalent about disclosing my MS. Yet, I already felt a huge sense of relief that I had told my boss. Colleagues assured me they would not share my MS revelation unless I wanted them to.

Day-to-day work did not change. Any flareups did not affect my productivity as the DMT and constant monitoring by my MS healthcare team showed the disease was manageable and stable. And, having disclosed at work, I felt more comfortable requesting time off to attend the annual National MS Society Public Policy Conference in Washington, D.C.

Opening up

A year later, a Wall Street Journal health correspondent who was working on an article about disclosing MS at work contacted me. We met several times for extensive interviews, and she also spoke with Harris. I decided to tell my staff about the upcoming article.

Coincidentally, a full staff meeting had been scheduled the day that the article appeared on March 31, 2005, on the newspaper's front page. With the New York staff gathered in a conference room and others across the country and around the world on the phone listening in, Harris held up the paper, declared that it was an example of courage, and saluted me for sharing my story of dealing with MS.

In the 18 years after I disclosed, work continued normally, and I continued to travel extensively. Conversations at work about MS were episodic, usually initiated by a colleague who had a family connection to MS and sought advice.

"Ken, you taught us all how to face difficulty, how to face illness, how to face our friends, how to face our colleagues, and to do it with dignity and with resilience," said one longtime colleague, who recalled how she had consulted with me about her relative living with MS.

Another colleague who had joined the AJC staff only four years earlier learned about my MS when I sought a donation for the National Multiple Sclerosis Society's Walk MS, and she told me about her mother-in-law and sister-in-law.

"With your encouragement, I shared your Wall Street Journal article on your experience, and it was a great source of consolation for them," she said.

Revealing one's MS is not a simple decision. Worried about what the reaction might be, I had agonized for months over whether to tell my employer and, after deciding that I must, when would be the best time to disclose. In the end, reflecting on our close, cooperative and productive relationship, I felt comfortable taking the risk of sharing my secret with Harris.

So, while comments about my MS were not expected at the celebration of my career, they were most welcome and deeply moving. To be commended by colleagues with whom I worked closely for a quarter century for handling a personal health matter is invaluable.

While I have retired from AJC, I continue to engage in issues and concerns that have been important in my personal and professional life. Deepening my involvement with the Society, and the issues those of us living with MS face, is a top priority.

Kenneth Bandler is a member of the board of trustees of the National Multiple Sclerosis Society's Greater New York City-Long Island chapter.