



When Neurologic Illness Hits Home — A Blessing and a Curse

BY ORLY AVITZUR, MD

Neurologists don't need to develop an illness to treat patients with compassion. Yet, an illness that strikes us or a member of our family elicits a unique perspective that can connect us more intimately with the human side of medical care. And when that illness is a neurologic condition, the added knowledge can be both a blessing and a curse.

This was the case for Alan Pestronk, MD, professor in the departments of neurology, pathology, and immunology at the Washington School University School of Medicine, where he had moved to run the neuromuscular group. In March 1993, when his former wife, Ilene Edison — a psychotherapist he had met when he was an intern — complained of being tired after a day with her grandchildren and had difficulty getting up from a chair and going up stairs, he became immediately worried. Dr. Pestronk examined her at their kitchen table and the worst came to mind. A colleague performed an EMG and muscle biopsy and confirmed her diagnosis — a variant of amyotrophic lateral sclerosis (ALS) without upper motor neuron signs.

"I read biopsies myself every Saturday morning and after seeing Ilene's on that particular morning, I asked her to come to my office, took a deep breath, and gave her the bad news," he recalled.

Being a neuromuscular expert made it a great deal easier, Dr. Pestronk acknowledged. "The hardest thing is recognizing the reality that there is no treatment that clearly alters the course of the disease, and the sooner that one knows that it's true, the better," he said. What's essential, he added, is that patients envision their life three months ahead so that they have the equipment and resources



DR. ORLY AVITZUR

needed to make adjustments to the progression of the disease. The first neurotrophic factor treatment trial was just underway at Washington University, and Dr. Pestronk was able to get his wife compassionate use without actually enrolling her in the trial.

"An underappreciated value to clinical trials," he explained, "is the excellent care that is provided by a multidisciplinary team." As Ilene became weaker, Dr. Pestronk also reconstructed their home, building an elevator so that his wife could move between floors. She died one year after the onset of symptoms.

Over the past 16 years since Ilene's death, Dr. Pestronk has been seeing patients with ALS and running clinical trials. His wife's illness gave him a keen appreciation of the subtleties of treating patients with diseases whose underlying causes cannot be modified. "It made me acutely aware of the role the neurologist

can play and the huge role other professionals — social workers, occupational therapists, physical therapists, respiratory therapists, pulmonologists — can play in making patients comfortable," he added. His experience also taught him how important it is to treat the caregiver. "Many terrible things can happen," he said, recalling a time when his wife was alone and fell in the bathroom, unable to move.

The second question Dr. Pestronk asks almost every time a patient comes in is "How's the caregiver?" "I try to make sure that someone comes in to the house to relieve the caregiver for periods during every week," he said, conceding how frustrated and exhausted he had become at times.

FRUSTRATIONS WITH PHYSICIANS

Jay H. Rosenberg, MD, was also angry for a long time after his wife, Judy, died. She had been diagnosed with multiple sclerosis (MS) soon after they got married and later developed breast cancer and a primary brain tumor. Dr. Rosenberg was frustrated with the physicians who were unable to help her when she developed an autonomic syndrome: with her oncologist whose approach to the recurrence of breast cancer seemed arbitrary, her surgeon for delaying the placement of a feeding tube when her weight plummeted to eighty pounds, and the medical system in general, which he at times found uncaring.

Like Dr. Pestronk, the experience made him more aware not only of the patient's struggles, but also of the impact on the family, the feelings of the spouse and children, and the powerful influence physicians can have if they are willing to listen and share with them. "We're taught that the white coat is the boundary, but maybe

it's not the right boundary," he said. Instead, he discovered that when he began to reveal to his patients that his wife had MS, it made a difference in their willingness to address the social and emotional issues related to the medical problems.

Dealing with illness and death has transformed the way Dr. Rosenberg practices neurology and cares for the large number of MS patients in his practice. "I understand the human trauma and look differently at the whole dying process. I'm willing to talk about death now, and listen to what patients are saying," he explained. "My whole practice has changed."

A TRANSFORMATIVE CAREER SHIFT

At times, a family member's illness can not only profoundly affect the way a physician practices, but can also chart a new course for a medical career. So it was with John A. Kessler, MD, chair of the Department of Neurology at the Northwestern University Feinberg School of Medicine, when in 2001, his then 15-year-old daughter suffered a spinal cord injury from a skiing accident. He spoke about the transformation in the Peabody award-winning documentary "Mapping Stem Cell Research: Terra Incognita."

"I really knew nothing about spinal cord injury except what I read in passing," he said. "I really knew nothing about the problem of regenerating axons. The day of the accident I decided that's what I'm going to do," and thus the Spinal Cord Injury Project was born. [Dr. Kessler describes the project as an effort to use nanoengineered materials to facilitate regeneration after spinal cord injury and examine the combined use of this material with various types of stem cells.]

"This becomes an obsession, it be-

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Ask the Neuroethicist

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patients' decisions to have home ventilator therapy. But it would be wrong for physicians to wield the costs of care as a bludgeon to intimidate or coerce patients and family members into agreeing with the physician's decision.

Some physicians and nurses find it psychologically difficult to order extu-

bation even after tracheal positive-pressure ventilation has been validly refused by an ALS patient. Other physicians also may be uncertain or fearful of medicolegal consequences when a patient dies after refusing life-sustaining therapy or believe that this activity violates their personal moral code. Some of these obstacles are amenable to education about clinical practice guidelines and others resolve with more experience in conducting this activity. But if a physician

remains unwilling to order extubation after further tracheal positive-pressure ventilation has been validly refused by an ALS patient — on the grounds that it violates the physician's personal moral code — the physician should attempt to transfer the patient to another physician who is willing to carry out the patient's wishes. While it is true that physicians are not required to perform medical practices that they regard as unethical, their conscientious opting out of stop-

ping therapy that a capacitated patient has validly refused should not deprive a patient of the right to refuse life-sustaining therapy. •

Dr. Bernat is professor of neurology and medicine at Dartmouth Medical School. He was the former chair of the AAN Ethics Law & Humanities Committee and is the author of Ethical Issues in Neurology, 3rd ed. (Lippincott Williams & Wilkins, 2008).

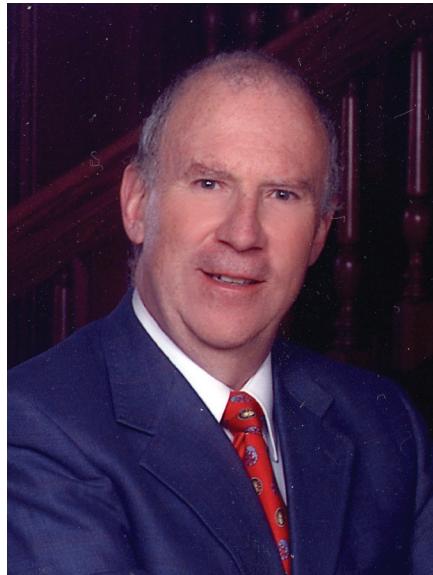
In Practice

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comes the driving force to life. There is no clinical dissociation from this... this is a very personal issue now," Dr. Kessler explained in the documentary.

EMPATHY FOR THE PATIENT

It becomes even more personal when the neurologist is affected by a neurological condition, even temporarily. About five years ago, Roy Katzin, MD was wrestling with his 15-year-old son, who accidentally broke his nose. A few days later, during the nasal repair, Dr. Katzin aspirated and developed pneumonia. He was admitted to one of his hospitals in Boca Raton, FL, where he had been in private practice for 23 years, and treatment included a course of intravenous steroids. Dr. Katzin, who developed severe delirium, recalls crying for his mother and his wife and calling his internist to insist that he be transferred to a different hospital for no apparent reason. Once he improved, he became aware of medication errors made by staff — some of which he could correct. For example, he inter-



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rupted the intravenous administration of the wrong antibiotic in the wrong dose by reading the IV bag label while it was being hung.

"I survived the experience and developed a heightened sense of empathy for those confused and disoriented in the hospital setting," Dr. Katzin said. He now writes orders to orient every delirium patient each shift and to keep each of those patients near an open window 24/7 so they can tell day from night.

One of the most common neurological conditions affecting neurologists is migraine. According to a 2003 paper in *Neurology*, the one-year-prevalence of migraine in American headache specialists is 66 percent and in neurologists 40.9 percent, compared with 12 percent of adults with migraines per year in the US. The high prevalence in neurologists has been confirmed in other countries including Canada, Germany, Spain, and Taiwan. Thirty percent of the headache specialists who were migraineurs said that their own migraine was one factor, among others, that had led them to become headache specialists.

Mark Stillman, MD, director of the Section for Headache and Pain in the Neurological Institute Cleveland Clinic

Department of Neurology, has suffered from migraine since he was a child. Like other migraine specialists, he understands the concerns of his patients because he has experienced them as well. His examination room is dark, and he uses incandescent light in his office because fluorescent lighting triggers a headache.

"When a patient relates that to you, historically there is a camaraderie, a confederacy of dunces," he said. "We all swap stories."

Dr. Stillman's experience has also helped him understand that regardless of how subjective pain can be, it's important to take patients at face value. "Many clinicians tend to discount patients and say 'that's nothing'; they don't realize that it's very disabling," he said, adding, "You have to believe what the patient tells you."•

*Dr. Avitzur, a neurologist in private practice in Tarrytown, NY, holds academic appointments at Yale University School of Medicine and New York Medical College. She is also the editor-in-chief of the AAN Web site, **AAN.com**, and chair of the AAN Practice Management and Technology Subcommittee.*