



Multiple Sclerosis

“Hitting the Mattress with MS” (January/February 2009) should be mandatory reading for anyone who has multiple sclerosis (MS) or lives with someone who does. As an MS patient, the explanation of the problems around sleeping was right on. I suffer terribly at night with spasms, pain, and tingling and have lost the ability to turn over lying down. Plus, I wake up approximately every two hours having to go to the bathroom.

—Rachael Kunkel
Hudson, FL

The Cost of Care

Your recent editorial on the cost of care really hit home for me as the mother of a 22-year-old with a seizure disorder. My daughter has been taking two generic anti-epileptic drugs for her condition, as was approved by HMO. After being seizure-free for years, she had a seizure recently while riding her bicycle, and tests in the ER showed her medication blood levels were low. We learned from her neurologist that generics generally work poorly for seizure disorder, but many health insurers deny brand name drugs anyway due to the cost, even if the doctor specifies ‘no substitutes.’ This leaves the patient with the choice of the often-ineffective generic or paying out-of-pocket for the brand-name drug. Usually there is no appeal policy, so the patient is stuck.

—Holly T. Tyler
Santa Cruz, CA

Assisted Suicide

Thank you for addressing such an important and contentious topic (“Assisted Suicide Legal in Washington,” Jan/Feb 2009) and for clarifying the difference between assisted suicide and euthanasia.

The author states that many people suffering from neurological diseases would not be able to take advantage of assisted suicide—even if legal—because they would be physically incapable of self-administering the drugs by the time they are six months from probable death. I think a way to ensure an individual’s right in this area would be to prepare an advance directive at the time of diagnosis. Why would someone with a terminal disease have to wait until six months of death, especially when the illness will rob them of the ability to physically self-administer the drugs?

A mandatory (or even voluntary) advance directive would also allow someone to make their wishes known while they are cognitively competent to do so. Then, if someone asks for a prescription to end their life at a point when there is a question about their mental competency (due to disease progression), the request can be compared to a recent advance directive.

It is not comforting to some of us that we may have to choose a messy or painful way to end our lives if faced with a debilitating, terminal illness because we can’t trust that reason and not emotion will rule the day.

—Stephanie H. Corkran, M.A.
San Diego, CA

Seizure Dogs

On the Letters page of the Jan/Feb 2009 issue, John Trefil, M.D., asked where he could obtain a seizure-alert dog for his daughter. Dr. Trefil should contact Canine Companions for Independence. This is an excellent non-profit that should suit her needs very well:

**Canine Companions for
Independence**
**Nat. Headquarters & NW
Regional Center**

**2965 Dutton Ave., P.O. Box 446
Santa Rosa, CA, 95402-0466
Phone: 707-577-1700.**

—Carol Stockbridge
Walnut Creek, CA

Neurology Touches Us All

My interest in neurological disorders is personal. I survived a “neurological incident/brain injury” (subarachnoid cerebral aneurysm) and over the years have learned of neurological disorders diagnosed amongst family members and friends. These include a son diagnosed with Parkinson’s disease at age 45, a paternal nephew recently diagnosed at age 43 with multiple sclerosis, a 38-year-old maternal nephew suffering lingering symptoms from a traumatic brain injury, and a close friend who has suffered recurring strokes (the more recent severely affected her ability to communicate verbally...and she was known as a great conversationalist!). Please continue with the publication. Know that I have referred it to many friends and family members.

—Lorrie G. Goodrich

CRPS

Thank you for your article (“More than a Feeling,” Mar/Apr 2009) about complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy