Locked-In Syndrome

I read your review of the movie *The Diving Bell and the Butterfly* in the Nov/Dec issue. People should go see this unbelievable story of courage. I was diagnosed with locked-in syndrome in January 2004 after I suffered a brain-stem stroke. Medical professionals have sometimes said cruel things in earshot of me because they thought I couldn't understand. For example, they have sometimes talked about having no hope that I would get better.

I'm better along in my recovery than some people. There are many things I can do, such as walk with the aid of a walker. This is a far cry from the bleak predictions of some of my doctors.

Two other books have been written on locked-in syndrome: *Locked-In, Locked Out*, by a prominent doctor named Shaw Jennings who suffered locked-in syndrome; and *Kate's Journey*, by Kate Adamson. Both of these survivors give the reader hope no matter how difficult the future seems.

—Alex Malon
Cedar Lake, IN

Trigeminal Neuralgia Resources

In the July/August 2007 issue of *Neurology Now*, Dr. Charles E. Argoff answered the question, "Are there drugs to control the unbearable pain of trigeminal neuralgia?" His answers were fine, but most of us TN patients are well aware of all the drugs on the market, and unfortunately most don't work. I've tried every drug, including a few at the VA that Dr. Argoff didn't mention, and all to no avail.

Trigeminal neuralgia patients may not be aware that surgery is available if drugs don't work. I found out about the surgery from a nonprofit group called the Trigeminal Neuralgia Association. Patients can write or call them to receive a huge packet of information and a bimonthly newsletter.

Trigeminal Neuralgia Association
2801 SW Archer Rd.
Gainesville, FL, 32608
352-376-9955.

—Frank Slason
Somerville, ME

Neurology and Creativity

Thank you for your publication about neurological disorders, research, and the latest therapies. As someone who suffered a brain injury back in 1990, I can still remember how frustrating it was to find informative material about my condition.

At the time, I was diagnosed with traumatic brain injury/concussion. Shortly after I returned home from a rehab center, my husband bought some paints and an easel home. He's really bad at Pictionary, so I didn't understand, until he said it was for me. I had done some sketching in college but knew nothing about colors or oils. When I finally got up the nerve to put the brush to the canvas, it was as if it was familiar to me and helped me deal with the pain. Since then, I haven't stopped painting and I have used art in working with other brain-injured people. I am now a facilitator at a children's bereavement center, where art is very therapeutic in helping the children cope with inner pain.

—Linda Sciarra
Wakefield, RI

THE EDITOR RESPONDS: Thank you, Linda. We'll check out your paintings online (**muralandartbylinda.com**). And we'd like to remind everyone that we're considering publishing a book of artwork from *Neurology Now* readers, so stay tuned.

Parkinson's and Depression

I was impressed by your article, "Parkinson's and the Black Dog," in your July/August 2007 issue.

In my day-to-day work with many individuals from the PD community, it is apparent that depression often goes underdiagnosed and undertreated. Though the statistics point out that 30 to 40 percent of those diagnosed with PD exhibit a degree of clinical depression, I find it much more prevalent in the community we work with.

Patients experiencing depression often become reclusive and separate themselves from the services that may be available in their community. Constantly feeling fatigued makes it even more difficult to instigate those activities that benefit the patient—exercise, socialization, and other self-care strategies.

Thank you for bringing more attention to a prominent and debilitating non-motor symptom of PD.

—Bill Bell, Executive Director
Northwest Parkinson's Foundation
Seattle, WA
1-877-980-7500
hopeforparkinsons.org

Transverse Myelitis

Please do an article regarding transverse myelitis (TM). I have had TM for 9 years

but was only diagnosed about 2 years ago. I belong to an on-line TM support group and we are all extremely confused about every aspect of this disease. It seems that we all get different information from our doctors and we just do not know which ones to believe. Can TM turn into multiple sclerosis and vice-versa? Will we ever get any better? Can we really believe that all of this was caused by a virus? What happens if we catch another virus somewhere down the line?

It would also be extremely helpful to let everyone know what the symptoms of TM are so they can get immediate medical attention and perhaps be put on intravenous steroids to try to avoid so much damage to the spinal cord. Is there any hope for TM patients in regards to stem cell research? Please enlighten us if possible.

—Ellie K. May
Arlington, TX

THE EDITOR RESPONDS: Thank you for your letter, Ellie. Go to our Web site (**neurologynow.com**) for an article about Allen Rucker, the well-known Hollywood writer who has TM. His book *The Best Seat in the House: How I Woke Up One Tuesday and Was Paralyzed for Life* is an insightful and funny chronicle of his experience with the disease.

Support for Spouses

I am the spousal caregiver of a 64-year-old husband with either early-onset Alzheimer's or frontotemporal dementia. My purpose in writing is to mention a couple of resources that I think should be mentioned in your Resource Central section. One is the wonderful organization Well Spouse (**wellspouse.org**) for spousal caregivers. Many members of Well Spouse, though not all, are caring for people with protracted neurological ailments, from stroke to Parkinson's to the family of dementias.

The other is the Frontotemporal Dementia Association—a terrific resource for those struggling with this group of little-understood diseases. (**ftd-picks.org**)

Thank you for your fine periodical.

—Rachel Hadas, Ph.D.
Rutgers University, NJ

SEND US MORE ARTWORK!

We want to see your drawings, paintings, photos, sculptures, etc. Although the 2007 contest is closed—the winning entry appeared in "Speak Up" (page 48 of Nov/Dec 2007)—we would like to showcase more reader art on our Web site, **neurologynow.com**.

The work should relate to living with a neurological condition in some way. Ideally, it should communicate what it's like to live with a neurological condition or someone who has a neurological condition. Please include a brief (50-100 word) bio and artist's statement.

You can send images of your art via email to **neurologynow@lwwny.com**. Or, you can send the original work (or photos of that work) to:

Wolters Kluwer Health, 333 Seventh Ave., 19th Floor,
New York, NY 10001, Attn: Neurology Now

Please enclose a stamped, self-addressed envelope so that we can return the materials to you by mail.

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YOUR VOICES

LETTERS TO THE EDITOR: Correspondence for publication on this LETTERS page must include name, address, and daytime phone number, and may be edited for purposes of space and clarity. It should be e-mailed to neurologynow@lwwny.com, faxed to 646-674-6500, or mailed to 333 Seventh Ave., 19th Floor, New York, NY 10001.

PERSONAL ESSAYS: The SPEAK UP essay is a forum for people who live with neurological conditions and those who care for them. Submissions should be kept to 600 words and sent to the addresses above.

ASK THE EXPERTS: If you have a question for a doctor to answer in our ASK THE EXPERTS department, send it to the addresses above.

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You may order a subscription—available for free to individuals with a neurological disorder and their families and caregivers—through the following methods.

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