



# A Lot of Nerve

Funding cuts for nerve studies will hit neurology patients hard.

BY GINA SHAW

On a visit to her daughters in Ohio in 2009, 85-year-old Ellen Bechtol unexpectedly developed shortness of breath and felt lightheaded. She went to a hospital emergency room, where her condition rapidly deteriorated: she suddenly collapsed, completely unresponsive, with her pupils fixed and dilated. Within 48 hours, she was in the intensive care unit (ICU) at University Hospitals Case Medical Center in Cleveland, where doctors told her family that although they had no explanation for what had caused her condition, Bechtol appeared to be brain dead. (For more on brain death, go to <http://bit.ly/bQM7YN>.) The family considered withdrawing life support, but her distraught daughters asked to think about it overnight.

One of the ICU doctors decided to order a study called an electromyogram (EMG), which measures the electrical impulses of muscles at rest and during contraction. Neurologist David Preston, M.D., wanted to rule out an unusual neuromuscular problem that might be paralyzing Bechtol. As he performed the EMG, Dr. Preston immediately saw that the results were abnormal and suspected botulism—a rare, potentially fatal, paralyzing bacterial infection.

Dr. Preston—and the EMG—proved to be right. The botulism infection was ultimately traced to an infected cut on Ellen's leg. The botulism spores had been deposited in the wound and then sealed off from the air by a large blood clot that developed over the wound because she was taking the anti-clotting drug warfarin (brand name Coumadin). The bacteria responsible for botulism will only grow in an environment without air.

"Several months later, she walked into my office with her daughters. Her mental state was completely normal, and all her cranial nerve function had returned to normal," Dr. Preston says. "The EMG



**NO LONGER COVERED** Man undergoing an electromyography (EMG) test to examine the contraction of his arm muscle in response to electrical stimulation.

study was the critical study that literally made the difference between life and death. Without it, care would have been withdrawn the next day and the patient would have expired."

## REIMBURSEMENT CUTS

Electromyograms aren't just used to diagnose botulism. Along with nerve conduction studies, which measure how well and how fast the nerves send electrical signals, EMGs are important primary diagnostic tools for a wide range of neurologic conditions, including (but not limited to) peripheral neuropathy and other neuromuscular diseases such as amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), myasthenia gravis, muscular dystrophy, and radiculopathy. (Peripheral neuropathy occurs when the nerves that send messages from the brain and spinal cord to other parts of the body—arms, legs, hands, and feet—

are damaged or destroyed.) In general, if a person has unexplained numbness, tingling, burning, pain, or muscle weakness, a doctor may conduct an EMG.

But in an unexpected decision at the end of last year, the Centers for Medicare and Medicaid Services (CMS) announced that it would cut reimbursement payments to the doctors conducting these studies by anywhere from 30 percent to 70 percent. Those cuts went into effect as of January 1, leaving neurologists with only two months to prepare for the new fee structure and no opportunity to provide official comment in advance of the final rule. Private insurers have already begun to institute similar drastic cuts, say many neurologists.

The slashed reimbursement rates are likely to affect people with neurologic conditions in two ways, says A. Gordon Smith, M.D., professor of neurology and chief of neuromuscular medicine at the

University of Utah. “First, there is access to EMGs and nerve conduction studies. The number of neurologists doing these studies will almost certainly drop, almost immediately. Outside of larger cities, patients will probably not have ready access to these tests.”

Dr. Preston warns: “With such dramatic cuts, electrodiagnostic studies will be used much less frequently, and important diagnoses will be missed.”

Second, cuts to reimbursement may drive small neurology practices out of business, affecting access to care.

### THE IMPORTANCE OF NERVE STUDIES

That worries Leslie (she has asked that her full name not be used), a 55-year-old woman from Massachusetts who developed excruciatingly painful neuropathy in the fall of 2006. Her condition progressed so rapidly that within a year, she was on disability, had to cede partial custody of her elementary-school aged children to her ex-husband, and was expecting to soon enter a nursing home. Fortunately, treatment in spring 2008 with intravenous immunoglobulin (IVIg) reversed most of her symptoms, bringing Leslie’s life almost back to normal.

“EMGs and nerve conduction studies were an essential step in diagnosing my neuropathy,” Leslie says. “Without them, I couldn’t have gotten a diagnosis or treatment. And without an EMG-based diagnosis, there would have been no coverage for the treatment. Many people in my neuropathy support group were told the pain was ‘all in their head’ many times before they finally got an EMG to confirm their condition.”

Delays in diagnosis are already common, according to The Neuropathy Association ([neuropathy.org](http://neuropathy.org)). According to a national survey (<http://bit.ly/J0wGSQ>), more than half of all neuropathy patients go two years or more between onset of

symptoms and getting a confirmed diagnosis, during which irreparable nerve damage continues to occur.

But it’s not just access to EMG and nerve conduction studies that is threatened. “This funding was a big part of reimbursement for some neurology practices,” says Elaine Jones, M.D. and Fellow of the American Academy of Neurology (AAN). Dr. Jones practices in Bristol, RI, and chairs the AAN’s Government Relations Committee. “It will be harder for some small groups to stay in business. As a result, there will be longer wait times for patients. I think we’re already starting to see this. I’ve always made it a prior-

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—DAVID PRESTON, M.D.

ity not to have more than a one-month wait time for new patients, but today I have a three-month wait time. That’s ballooned just since December. I think there are fewer neurologists out there seeing patients already.”

In practices that stay open, the quality of care may be affected. “Even in large healthcare systems, these cuts are likely to have an effect,” says Dr. Smith. “Many patients require a great deal of face-to-face time with their neurologist. Just this morning, I saw a patient who commented that when he sees his primary care

provider, it’s an assembly line. But I spent half an hour with him and had the time to talk about his problems in more detail. That may change as the impact of these cuts begins to be felt more.”

### WHAT YOU CAN DO

The AAN has been meeting with both CMS officials and members of Congress to try to get the decision reversed or at least make the cuts less drastic. But so far both groups have been unreceptive. “When we talk to them, they say that they’re not hearing that this is a problem—that patients aren’t telling them that they are having trouble getting these studies or having to wait a long time to get in to see a neurologist,” Dr. Jones says.

That’s where patients come in, says Dr. Jones. “If you’re having long waits to see your neurologist, if you can’t get an appointment for an EMG or another one of these studies, reach out to your state and federal elected officials. Patients have to get vocal too about access to care. It’s worked in the past—for example, when the multiple sclerosis drug natalizumab (Tysabri) was taken off the market, patients played a major role in bringing it back,” she says.

Several patient advocacy and professional organizations are fighting to restore the lost funding. One that is leading the advocacy charge for patients is The Neuropathy Association. They have asked patients who are encountering access problems to go to Medicare’s online complaint form ([medicare.gov/medicarecomplaintform/home.aspx](http://medicare.gov/medicarecomplaintform/home.aspx)) to report their experiences.

“When patients speak out, it has an impact,” says Dr. Jones. “You have more power than you think.” NN

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