Fight Smart, Not Just Hard

How I'd battle ALS if it happened to me.

BY RICHARD S. BEDLACK, M.D., PH.D., M.SC.

On the beach this summer, reading an old book of poetry, I looked up and saw a sign like the one below. Maybe it was heat stroke or the daiquiri I was sipping, but I came to appreciate an odd relationship between the poem in front of me and that sign. The poem was Dylan Thomas's famous meditation on struggling against death, "Do not go gentle into that good night." I read it and imagined what I would do if I got caught in a rip current. As that current started to pull me out and under, I'm sure I would "rage, rage against the dying of the light," as the poem implores. I'd give it all I had. My first instinct, though, wouldn't be to swim diagonally, as the sign recommends. Instead, I would swim as hard as I could straight toward the shore. And chances are I'd eventually become exhausted and drown.

The sign promised a better way to "burn and rave." Though this counterintuitive approach couldn't guarantee my survival, it certainly would increase the chances of it.

Later, back at work in the Duke ALS clinic and nursing a sunburn, I thought about my day at the beach and how it related to my experience with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease). What would I do if I received a diagnosis of ALS, or if one of my loved ones did? Like most of the 1,000 or so patients with ALS and their caregivers that I have seen over my last decade in this field, I'm sure I would fight it—in Thomas's words, "blaze like meteors" against it. But without all my years of scientific and on-the job-training, would I know the best direction to go in?

A Google search on ALS would certainly tempt me to consider that the diagnosis was wrong. Maybe it's Lyme disease or heavy metal poisoning, I would wonder. Further browsing of the Internet and conversation in online chat rooms would make me want to try a number of alternative or off-label therapies for the disease—things like chelation, unusual diets, or maybe even a "stem cell transplant" in a mysterious clinic in a foreign country.

But like the person who made the sign on the beach, I have learned that there is a better way. I've seen data showing that the diagnosis of ALS, when made by an experienced neurologist, is almost always correct. Therefore, once I had an opinion from an ALS expert, I wouldn't need to expend a lot of energy considering other possibilities.

In addition, ALS experts have already looked critically at many of the alternative and off-label options being pursued and found no merit to them. Thus, instead of furiously chasing these down, I would pursue the treatments that have been shown to prolong life and/or preserve quality of life; these include riluzole, early bipap, optimal nutrition, and care in a multi-disciplinary clinic.

Realizing that research is the only sure way that I (and everyone else with ALS now and later) will get closer to a cure, I would try to participate in every study that I could, monitoring legitimate Web sites like **clinicaltrials.gov** to look for opportunities. Knowing that this is a rare disease, and one in which research funding is desperately needed, I would "burn and rave" as an advocate, doing all I could to raise awareness and funds for groups like the ALS Association (**alsa.org**) and the Muscular Dystrophy Association (**mda.org**). I would travel to National ALS Advocacy Day (**alsa.org/policy/alsday.cfm**) every year to make sure my elected representatives understand how tough this disease is and that they continue to support programs that help ALS patients and caregivers. I would stay in this fight even if my loved one eventually lost his personal battle with the disease.

In the end, would the things I've learned ultimately save me or my loved one from ALS? Unfortunately, they might not. Neither Thomas's poem nor the sign on the beach promise salvation. The sign, like my experience treating people with ALS, simply maps a path which optimizes the possibility that something good will come from all the valiant efforts. Whether it's a rip current or a terrible disease like ALS, let us all continue to "rage against the dying of the light," but in a direction that makes sense. NN

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