

Bringing stroke out of the shadows

Shame, lack of attention still surround disease despite its prevalence

By Kris Appel

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Stroke is a devastating disease. It is sudden, unlike cancer and diabetes, and it can happen to anyone, anytime, at any age. And it is common, affecting 4 out of 5 American families, according to the American Stroke Association. Yet stroke remains mostly hidden, out of the mainstream, neglected by the major fundraising events and ignored by the media.

Consider these statistics from the American Heart Association: Stroke is the leading cause of adult disability and the third-leading cause of death. About 6.4 million Americans are living with stroke. The estimated cost of stroke this year in U.S.: \$73 billion.

Yet where are the stroke celebrities? Where are the telethons and the day-long concerts? We have highly publicized treatments for heart disease; we all know someone who's had a stent or a bypass. But despite stroke's prevalence, only 38 percent of Americans know stroke warnings signs well enough to dial 911, and we often don't learn about stroke until it's too late.

I am the founder of a company that makes stroke rehabilitation devices. I recently conducted a direct mail campaign to self-identified stroke survivors, but a few stray letters ended up in the wrong mailboxes. What an insult! For two weeks, I had people writing unpleasant e-mails and calling my office to scream at me because I had (accidentally) called them a stroke survivor. One woman told me it was a "dirty trick" and that if I contacted her again she would call the police.

Why do so many feel angry about being called a stroke survivor by mistake? Cancer, a disease less hidden than stroke, was once considered shameful and its victims scorned. But money, research and awareness have made it much more easy to talk about cancer. Would this woman have been as incensed if I had written her a letter about being a cancer survivor?

Sept. 11 may have marked a turning point in the way we view survivors of stroke. Former CBS weatherman and news reporter Mark McEwen returned to network television for the first time since his 2005 stroke. True, it was just a weather report, but it was one of the few times we have seen a stroke survivor — still with some effects from the stroke — on live television. We saw Mark on TV, speaking a bit slowly, but still being Mark the reporter and capable adult. I'd like to think it won't be the last time we see him on network television.

Yes, we all remember Dick Clark returning to host New Year's Eve celebrations after his stroke, but this is almost the exception that proves the rule. If there are more than 6 million stroke survivors living in the U.S., why aren't we seeing more of them on television — or in our workplaces?

We need more role models. We need stroke survivors to come out of their homes and talk to us. And we need to listen. We need to be patient. We need to understand this disease and find ways to bring it into the light. Most important of all, we need to change our attitude about stroke, so that we can begin to do a better job of preventing it.

Stroke survivors tend to have little organized representation. The effort to raise awareness, to educate, to prevent, and to treat will be a massive undertaking. Today is World Stroke Day, and the World Stroke Organization hopes to take the opportunity to give this disease the place it deserves on the global health agenda.

But until we become comfortable with the idea of stroke and are willing to talk about it, to acknowledge its toll on this country, it will remain in the dark. Let's view Mark McEwen's weather report on CBS as a small step out of the shadows.

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