

Man of steel: An MS hero



When positive comments are kryptonite

by **Ellen Robare**

A couple of years ago, we bought my husband, a comic book fan, a hat. On the front is the Superman logo, and on the back it says “Man of Steel.” He wears it often, and at times I can’t help but think just how appropriate it is for him to wear that label.

Yes, my husband has multiple sclerosis. Yet despite the ever-present and unpredictable company of severe numbness, stabbing pain and crushing fatigue caused by this disease, he manages to maintain a schedule at an unforgiving job that would exhaust a healthy person—and still finds time to do things at home and spend time with his teenage son. His alarm goes off at 4:30 a.m. each day, and it is rare that he gets home before 4 p.m.

It’s been my observation that many people who have MS are like him—tough as nails. In fact, they manage to function so well that others don’t have any idea what they are going through. I can’t count the number of times that people have said to me, upon learning that my

husband has MS, “My aunt/uncle/friend/cousin/acquaintance has that, and is doing fine.” Or, “Isn’t it great that they have all kinds of new medicines for that now?”

People think they’re being helpful, or cheering me up—and I honestly do appreciate the attempt—but sometimes I wonder if nodding and smiling isn’t perpetuating the idea that MS isn’t that big of a deal. I wonder if these folks believe that MS is more or less just an inconvenience, that medical science just about has it beat, or even that it’s not a cause that still needs funding for research.

Unfortunately, the truth is that there is still no cure for MS. While research indicates we are tantalizingly close to figuring it out, it’s a long road from promising research to a commercially available cure. Certainly, new medicines can aid with symptoms and even slow disease progression, and I hesitate to call them anything less than fantastic (who knows where we’d be without them).

However, they still are strong drugs with sometimes unpleasant delivery systems (such as stabbing yourself with a 2-inch needle) and sometimes scary side effects (would you like a side of heart damage with that?) that are intimidating to say the least.

I’ve come to the conclusion that the real reason so many people know someone with MS who is doing “fine” is not because we have it nearly beat, but because so many people who have MS are, like my husband, putting forth a Herculean effort on a daily basis to stay active, to not lose ground, to stay in the game. Man of Steel? Damn straight. In fact, now that I think about it, it’s probably an understatement. People with MS could probably show Clark Kent a thing or two.

So, I’d like to make a suggestion. The next time a friend tells you that she or a loved one has MS, consider ditching the “people with MS do just fine” speech. Your friend probably knows that appearing fine on the outside is a small part of a much bigger picture. Maybe curb your praise for those new medicines. Unless you’re a neurologist, your friend can probably school you on the latest available treatments—and their downsides.

Minimizing the situation won’t make someone with MS feel better. But empathy just might. How about trying instead something as simple as, “I’m sorry, that has to be rough. How does he manage?” Better yet, ask that “fine” aunt/uncle/friend/cousin/acquaintance a little about what he or she really deals with on a daily basis, and you might find yourself adding, “I know someone who has that, and I am in awe of how he deals with all of it—I think he must be a superhero or something.”

Ellen Robare lives in Portage, Mich., with her husband, Randy, who was diagnosed with MS in 2003, and their son.

Ever felt others don’t understand what it’s like to live with MS? Share your story at [MSconnection.org](https://www.msconnection.org).