# @Momentum



# Approaching MS in our own ways

I am a woman with MS, and when I started reading your "Sense of self" article in the Spring 2018 issue, I thought, "Here we go again. Another doctor/lawyer/actor talking about how they turned their diagnosis and life into a positive experience for themselves and the community." How happy I was to read the variety of stories from different INDIVIDUALS who approach their own kind of MS in their own ways. I'm not saying that famous people do not have problems, but the problems are a bit different. We all deal with what we have of ourselves after and during our MS diagnosis. We all do the best we can with what we have. Life gives you what it gives you and those are the tools we have. I just call it reality. Thank you again for such a real article.

Lisa M., Pennsylvania

# Let's hear it! Share your thoughts and comments about this issue's stories.

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- Or send mail to **Momentum** Editor, National MS Society, 900 S. Broadway, Suite 200, Denver, Colorado, 80209. Letters to the editor must include your name and a way for our staff to contact you. Letters should be no more than 100 words and may be edited.

#### Keep going

I've enjoyed the past two issues very much. I've been struggling with my "sense of self" since I had to quit my job as a science writer in 1997. If I'm not a writer anymore, who am I? I think my coping style is much like <a href="Stacey Dorton's">Stacey Dorton's</a>: Prepare for the worst but hope for the best, and above all, keep going while you still can. I had been riding horses since I was 9 years old and my lifelong dream was to have horses, so I bought a pregnant mare. People (including my parents and neurologist at the time) said, "You can't do that, you have MS." But the horses gave me a reason to get up every morning—rain or snow, heat or cold. They gave me joy and physical exercise for 12 years before I had to give them up. Now, I have a huge photo album of mom and baby, and incredible memories of our many trail rides into the wilderness areas of the Rocky Mountains. What an empty life I would have had if I had listened to those naysayers who said, "You can't do that, you have MS."

#### Linda Brown, Colorado

## Leading a productive life

I want to express my appreciation for Lois Kipnis' letter to her adversary MS in "Dear adversary" (Spring 2018). I was diagnosed in 1970 at the age of 37 with relapsing-remitting MS. I am now 85 and have lived with MS for 48 years. Though I have had my struggles along the way, I am still leading a productive life. Like her, "I've fought to force you (MS) back." My youngest son was 6 at the time of my diagnosis and feared I was going to die. In the early years, I wasn't too sure of that myself or what the outcome would be. Thankfully, I have seen my grandchildren graduate from high school and college, as well as work in their chosen fields. I have had the privilege of seeing my two granddaughters marry and now am the great-grandmother of two. At the onset of MS, I had no idea of what the future held for me, but fight I did. Again, thank you for the encouraging words of Lois Kipnis.

#### Mary Lou Sharp, Ohio

#### **Color-coordinated canes**

After reading the article "Embarrassing MS symptoms" (Fall 2017), I would like to share my situation. When I was diagnosed with MS, I bought canes to match my clothes. Many people are so fascinated with my colorful canes they hardly notice I'm handicapped. A friend gave me a Santa cane many years ago, and even little kids stop me and want to look at the cane. This year, I needed a brace for my left foot and leg and I went to the orthotics person kicking and screaming, but he taught me a trick. If you get a white or even pink brace, others will look at it like a handicap, but if you get a print or bright color, people will know you are not ashamed of wearing it and even stop you and tell you how good it looks.

#### Fran Jenkins, Oregon

# Be more realistic

I was dismayed to see what appears to be a stock photo glamorizing disability in the article "<u>Vocal control</u>" (Winter 2017-18). The lead photo is of an unidentified couple: a beautiful, heavily made-up young woman embracing a handsome man with just the right amount of

stubble in a manual push wheelchair, clearly not a chair for anyone with much disability at all. The subject of the article was Michael Ogg, who described using his wheelchair with a joystick controlled by his chin. He is pictured secondarily in a large automated wheelchair. And he lives alone. There is no shortage of Hollywood films depicting beautiful young women falling for quadriplegics. However, I would expect the National MS Society to have a more nuanced view. My husband, Matt, became a quadriplegic due to MS three years ago at age 45. It has had a decidedly non-glamorous impact on our family of four despite his and our best efforts. A photo of Mr. Ogg alone would have been a more realistic editorial decision.

Sarah Poggi, Maryland

## Strength in faith

I am one of the many who has dealt with exacerbations of MS for decades, made worse later by a broadside car accident. I could go on and on, but the bottom line is we must still have strength in faith and do as much as it takes, no matter how long or the pain involved. I have learned to never give up, to do the needed things that will help my condition. I have gotten a PhD in nutrition from La Salle University and, since then, have helped others and myself to never give up, do what it takes to be stronger, and do more despite the pain of the disease or any other health conditions.

Christine M. Pantilione, PhD, New Jersey