# @Momentum



# You get me

I found so much that I related to in the Winter 2015-16 issue—so many "aha" moments. In "Pain, pain, go away," I recognized my symptoms when I read that neuropathic pain "can be caused by something as simple as the weight of a blanket." I have said that same thing. I also have cold sensitivity along with Raynaud's phenomenon, and experience my muscles "locking up" as described in "Warm up to winter." I recognized myself when I read in "Mingle all the way?" how holiday parties can be tough for people with MS. I am exhausted and hurting in the evening. Plus, the statement, "Parties are loud" is so true. The noise makes me feel anxious, like my nerves are frayed. When I "see" myself in your articles, I feel my experiences are acknowledged and understood, and that helps me.

Susan Hays, New York

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

- Tag your thoughts on **Twitter** <a href="mailto:oMSsociety">oMSsociety</a> using #Momentum.
- Like and comment on our page on Facebook.
- Email editor@nmss.org.
- 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.

# **Sharing our experiences**

Regarding the article on <u>living with pain</u>, it might be useful for the magazine to solicit and publish readers' methods for dealing with pain and other symptoms of MS. I suspect many have found unconventional methods that provide relief. For example, my go-to method is to take an ibuprofen with a glass of red wine. For some reason—and despite my doctor's skepticism—that combination provides significant, and often complete, relief.

I also currently manage my illness with diet and lifestyle. A few years after I was diagnosed, my wife and I began adopting the Mediterranean diet. We did not find it at all difficult to follow—it essentially is a diet high in fresh vegetables and fruits, with modest amounts of animal proteins.

I still have MS. There are days where I have episodes of pain, fatigue, numbness and spasms. But I have many more days than before that are completely symptom-free, and when I do have symptoms they usually last for only a few hours.

#### **Judson Roberts, Oregon**

**Editor's note:** While we don't have space in **Momentum** to publish all our readers' ideas for managing symptoms, we agree that sharing them is essential. Please visit <u>MSconnection.org</u> to share your ideas for managing pain and other symptoms, and to read how others handle it.

# Making winter work

I have a few ideas to share about your article "Warm up to winter." I live in northwestern Montana, where we deal with long, cold winters. I love where I live and have no intentions of moving for a more comfortable life. But I've learned two things that help to make life in the cold better.

First, a hot shower always works to warm me quickly. The other is an electric lap blanket, which tends to draw the pets to my lap. The pets also help to warm me! I keep blankets behind the living room furniture and also in the truck. Knowing I am likely to be cold, I always have myself covered. Hope this helps others.

Sue Cox, Montana

# Digital bonus: More letters from Momentum readers

## Mittens matter

There is much I could write about the Winter 2015-2016 edition, but I'll refrain from heaping too much praise on each and every contributor, and focus on "Warm up to winter." I will suggest that anyone living in a colder climate knows that mittens—down or sheepskin—are the best and only gear that should cover fingers and hands. Fleece mittens with leather palms are warm enough for driving, but not for walking, snowshoeing or skiing. Discussing

caps and boots would take at least another two paragraphs.

#### Mary K. Melrose, Wisconsin

### We are not alone

Thanks so much for "Warm up to winter." I've had Raynaud's disease since childhood, and MS since my mid-20s (I'm 44 now). It's nice to know I'm not the oddball person with MS who's wired backward! Cold weather, the freezer section of the grocery store, mixing cold ground meat to make meatballs—all make me cringe! I'm looking forward to trying some of the heated products that were suggested in the article.

#### **Erin Fucci, New Jersey**

I was excited to read the recent article concerning <u>cold intolerance</u>. I've had MS since I was 34. Living in northern Illinois, I get both extremes of weather. The heat does not bother me nearly as much as cold does. I never heard of anyone else suffering from cold symptoms. After reading the article I feel better that I am not all alone with my symptoms. Thanks for publishing it!

#### **Christine Kraft, Illinois**

# Party article praise

Your recent article, "Mingle all the way," by Julie Stachowiak, PhD, is spot on. I felt when I read it that I could have written it. Thanks for including such a meaningful article in **Momentum**.

#### **Debbie Harris, New Hampshire**

# Move beyond stigma

I really appreciated Sarah Wellington's article on medical cannabis advocacy ("Cannabis at the Capitol"). My husband has progressive MS and severe muscle spasms that are not controlled with conventional medication. He doesn't have access to medical cannabis and if he tried it illegally, it would jeopardize his career. It's critical that we continue to advocate and educate the public and our lawmakers to move beyond the stigma of marijuana as "pot" and begin seeing cannabis for the healing potential that it uniquely offers.

#### **Kimberly Price, Alabama**

# **Cannabis and pain**

I was interested to see articles on both <u>pain</u> and <u>cannabis</u> it the Winter 2015-16 issue. "Pain free" is an elusive goal for me, but my pain IS containable with cannabis.

At 63, diagnosed at 38, I have had many years to experiment with a variety of painmanagement approaches. I've had years o

f prescribed medications; some of them work with specific targets like restless leg syndrome and neuropathy, but the overall spikes in body pain were only temporarily abated with

hydrocodone. Yes, I was taking 50mg/day and after 10 years my body said, "ENOUGH!"

I started looking for pain relief a couple of years ago. [But] by sneaking around to obtain cannabis, I was jeopardizing my life and my marriage. My wife was a school teacher for 34 years and there was no funny business allowed in our home.

Finally, she saw the humiliation I felt with my limited movement, like when I had to literally lift my leg to get into our car. That was the day she accepted cannabis. At first it was, "Oh, do you have to?" but after a year of being "out," she sees cannabis as very effective. My therapy is minimal as the pain is abated immediately and lasts a couple of hours. I don't like smoking it and would rather use oil or edibles but they're not yet legal/available in my state. Perhaps once the Food and Drug Administration accepts cannabis as medicine as opposed to images supplied by the old movie, "Reefer Madness," those of us with constant body pain may have the quality of life where we may interact with the rest of society.

#### **Bruce Huff, Texas**

# **Acupuncture not always costly**

I read "Pain, pain, go away" (Winter 2015-16) anxiously to see what you had to say about the role of acupuncture. I agree that it can be costly, but there are options. At community acupuncture centers, acupuncturists treat everyone in one room. Insurance may not cover it but the cost is reasonable; it may be the same or even less than an insurance co-pay.

# Julie Power, Minnesota

# Live for today

Carla Ramos, who was interviewed in "Recognizing a relapse" (Winter 2015-16), reminded me of myself when I was first diagnosed. She was "riddled with concern and fearing a trip back to the hospital. The unpredictability of MS symptoms only added to her anxieties." I, too, worried when I was first diagnosed. I worried if I would be able to walk tomorrow or what would happen to my three young daughters if I couldn't take care of them. Then one day, it occurred to me that no one else knows about tomorrow either—even those who don't have MS. That thought has stuck with me for 25 years now and helps me let go of my fears.

#### Teresa Flora, Kansas

# Making lemonade

Regarding the letter from Steven Lovell in Massachusetts, who commented on "Aging with MS" (Fall 2015), saying: "I was depressed when I read I could have an 80 percent chance of getting the progressive form [of MS]. But at the same time I am grateful I now know there still could be some dark days ahead." Steve, there can be lemonade in this lemon. When my MS started to progress in 1987, I was a regional sales manager with an extensive travel schedule. Thinking ahead, I decided to pursue a PhD in order to have a teaching job when walking became more difficult. I am now ending a 21-year career as a professor of business administration. Even though I had to move to online teaching, it has been a rewarding

career—a career that would not have occurred to me had I not had those "dark days" ahead in mind. Think lemonade!

Janis Dietz, California