# @Momentum



# Readers sound off on bladder issues, service animals, yoga and more!



Illustration by Pushart

# Botox, baby!

Thank you for the informative article, "Yes, you can regain bladder control!" (Spring 2015). I have utilized every method from oral medications to self-catheterization, and most recently have had Botox injections. Hooray for Botox! I encourage anyone with similar problems to go to their urologist and inquire about this procedure. It is very quick, and three months later I am still having great success with bladder control. I do still use catheters, but only about twice a day now instead of four times. This doesn't have to be embarrassing; it can be totally freeing. I urge you to find help because it makes all the difference!

Lori LeBaron, Colorado

#### A great read

I always look forward to the new issue of **Momentum**. It is always filled with current information on MS, as well as problems that we have with the disease. I also like the personal pages by others who have MS and how they cope and overcome some situations. In the Spring 2015 issue, the article on bladder control was talking to me. I read **Momentum** from beginning to end in no time. Thanks for sending it to me. Please keep them coming.

Pat Clement, California

# 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 <u>Facebook</u>.
- Email <u>editor@nmss.org</u>.
- 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.

#### **Catheter success**

My wife, Emily, had MS for 64 years, from age 19 until her death in 2013 at age 83. She experienced the common urinary symptoms of frequency and urgency. Travel of several hundred miles became very difficult because of these symptoms; frantically looking for the next rest stop became routine.

The single most helpful medical intervention occurred when Emily was in her early 60s. She had a Foley indwelling catheter put in place. She never had to be concerned about these matters after that, whether traveling or in more routine living circumstances. In our/her experience, the often-expressed concern about the risk of infection with an indwelling catheter is greatly overrated. The important thing is to deal with it when symptoms develop. My wife's urologist never wanted to prescribe antibiotics unless there was (1) fever, (2) pain in the bladder area or (3) a significant amount of blood in the urine. This did occur on occasion and was handled satisfactorily when it did.

Tom Nicholas, Pennsylvania

### **Irritants not always obvious**

Thanks for bringing up the issue of avoiding irritants in the article on bladder control. This discussion should also emphasize that just as individuals with MS experience varying symptoms, individuals can react differently to a variety of irritants. Some antihistamines, like Benadryl, and some normal foods, such as real cocoa, are just a couple of the everyday items that can cause irregular bladder urgency. Selectively avoiding various items in your diet may allow you to narrow down your triggers so you can eliminate them from your diet.



Photo courtesy of Rita McMillan

## A horse of a different color

Thanks for "Animal attraction" in the Spring 2015 issue. My sister is a horse trainer and she trained a miniature horse, Tonka, to be a service animal for me. Miniature horses are the only animals other than dogs that are specifically called out as approved service animals in the Americans with Disabilities Act. Tonka will pick things up and give them to me if I drop them; he stands and lets me use him to pull myself up if I fall. He helps with my balance when I walk. He is trained to only step partway up or down a step or curb and allow me time to negotiate it. He is even potty trained. Tonka fits in the back of my car, and has been to doctor appointments with me at the Oregon Health & Science University. He rides in the elevator and on the sky tram to appointments. Best of all, he is wonderful company!

#### Rita McMillan, California

# Responsible pet owners

I want to comment on the article, "Animal attraction." As a pet owner and a person with MS, owning a dog is not just a privilege; it's a responsibility. Animals depend on us for, at minimum, food and shelter, and deserve much more. If you are considering taking a dog into your life, you need to think seriously about the commitment that dog ownership entails. Please also consider vaccinations, treatment for fleas and ticks, bathing and grooming, and veterinary bills in the list of questions to ask yourself. It is important to be the best pet owner you can be.

#### Karen Ramsey, Ohio

### A better look

I just pulled the new issue of **Momentum** from the mailbox. The article by Valerie Benko ("<u>Falling with grace</u>," Spring 2015) is something I relate to quite well. I too am a faller. I usually make a joke about it when I find myself on the ground or floor in public. I always tell

those concerned that I am a professional floor inspector, or that I just love the new flooring or sidewalk so much that I wanted a better look. Meanwhile, I am picking myself up and assessing any potential damage to my body. Thanks for all the great information.

Jessica Bougher, Georgia

# Yoga's surprising benefits

I was so glad to read the article on yoga ("Stretching your life," Spring 2015)! About five years ago, the National MS Society sent me info on some local classes with a certified instructor trained in yoga for MS, and it was fantastic! Whether you use a wheelchair, cane or walker you can still do yoga. The classes helped me with balance and pain. I still do some of the poses to this day, especially on really bad spasm days. So to everyone: Try it! You may be surprised—in a good way, of course.

Betty Maeyens, Indiana

# Digital bonus: More letters from Momentum readers

#### **Snow wonder**

As one of the adaptive skiing volunteers who has skied with John Pierce ("Ready, set, snow!") I'd like to let you know that Vicky Uhland's article in the Winter 2014-'15 **Momentum** was one of the best I have come across in 15 years of volunteering in these programs. Her research and exceptional writing skills are rare, and it was a great pleasure to see how she included information and material about the many different programs and opportunities that are available for people with all sorts of disabilities to enjoy outdoor sports.

I have forwarded the online links to the article to several of the programs I have volunteered with, in the hope that they will acquire (or already have on hand) copies for display and distribution. Many, many thanks for publishing this article. It was a real pleasure to read.

Peter Hogg, Vermont

#### Free to be

The article "Yes, you can regain bladder control," (Spring 2015) had lots of good information but I believe missed the best solution: self-catheterization. As a woman, I initially was horrified by the thought. However, it truly has given me my life back. I never think twice about going to the movies, going on a long car ride or going out of town. I now make the decision of when to use the facilities. And with pen-sized disposable catheters, there is no hygiene issue. There is absolutely no pain. Yes, it might take a few weeks to get used to, but once you've mastered it, freedom reigns. I've saved a fortune on disposable bladder protection products. I made a trip to South Africa two months after starting to self-cath. My only complaint is that they are prescription only. I wish I could visit any city and buy catheters at the pharmacy in a pinch. It's no different than inserting other feminine products

that are over the counter.

#### Janet Burt, Virginia

# **Cutting caffeine**

I was at my wit's end trying to obtain bladder control. I was just last week at the point of asking my doctor for that surgery that diverts urine to a collection bag that was mentioned at the end of "Yes, you can regain bladder control." However, I paid particular attention to the bulleted section headed "First line of treatment." The fifth paragraph down offered a solution I had not tried: "Limit caffeinated beverages (coffee, tea and soda)." Easy enough to do, and I was desperate enough to try just about anything. I stopped drinking coffee and sodas right then. Just like a miracle, the problems with incontinence stopped right then also. The headaches from withdrawal aren't any fun, but I've been able to manage. It's worth it to be able to make it to the bathroom on time now, not to be constantly leaking when I least expect it, and not to be stopping in every bathroom I pass. Great article; I hope it helps others like it helped me.

#### Patricia Shields, Missouri

Editor's note: Every person's situation is different, and eliminating or reducing caffeine may or may not be sufficient to solve an MS-related urinary problem, depending on what other central nervous system changes might be contributing to it.

# Dispose & go

I appreciated your article on urinary problems that accompany MS. Another suggestion is to use a disposable urinal, such as TravelJohn, which is a device that both men and women can insert in their underwear, and it holds quite a bit of urine. Whenever the need arises, one urinates and the urine mixes with a chemical in the device, turning it into a solid. The urinal can be disposed of later. This has saved me having to search for a bathroom when I am out where bathrooms are scarce.

# Margaret L., Illinois

# It might be the MS

I just read "Falling with Grace" (Spring 2015). I have been diagnosed with MS for 15 years, and have been relatively OK. But I have always been "clumsy." And the last few years, I have fallen a lot, mostly on flat surfaces, a beach, a rug, a sidewalk. It was not the MS, I said, with certainty. But the thought crept in: It might be. The falls might be slow motion and gentle, sometimes violent and physically hurtful. Stitches. Swollen knees. And worse, for me, a significant other who neither helped me nor seemed to worry when it happened. Sometimes, he'd say, "What was it this time?" or look the other way, look embarrassed, irritated.

A co-worker, on the other hand, would stop and help me up, or offer a steadying hand as I started down stairs. And a friend with MS finally said, "It might be the MS ..." This is hard. The

relationship has recently dissolved. The co-worker and friend are still there. And I am admitting, mostly to myself, "I think it's the MS." The co-worker, it turned out, had a mother with MS. And most of my friends know other people with the disease. On the whole, I am doing fine. I fall, and it is probably the MS. But, it's not the worst thing that could happen. Not with my dear friends.

Linda S. Bridges, Maine

# Area rugs a fall hazard

I enjoyed the Spring 2015 edition of **Momentum** very much. I especially liked Valerie Benko's article "Falling with Grace." I too consider it a successful fall when I don't bang my head! But no mention of area rugs? (They are surely my greatest hazard!)

Jessica Koock, New York



Photo courtesy of Patti Klein

#### Pet project

I read your article, "Animal attraction," in your Spring 2015 issue with great interest. I was diagnosed with MS in 2006. Since then, my diagnosis has forced me to "reinvent" myself, as it does with many people with MS. Often, after being diagnosed with a chronic illness like MS and adjusting your life to the challenges imposed by the diagnosis, you feel the need to give back. One of the organizations I have become involved with since I had to retire from my career of 25+ years as an anesthesiologist is Therapy Dogs Inc., an organization not mentioned in your list of "Pets at our Service." Through this wonderful volunteer group, a handler (such as me) and a dog (such as Elvis, my 7-year-old Norfolk terrier) visit various facilities—nursing homes, special needs centers, assisted living homes, libraries, etc.—on a regular basis, allowing social interaction and the known positive health benefits for all involved. I know that Elvis and I bring happiness and cheer to people by sharing smiles and joy on our visits.

# Rabbits' life spans not short

The Spring 2015 **Momentum** was my first introduction to your magazine, and I was impressed with the broad range of helpful pieces. I particularly enjoyed the article called "Animal Attraction." As an animal lover and former animal therapy volunteer, I can attest to the power of pets for anyone struggling with MS or other chronic conditions.

However, there is one thing I feel compelled to write about. There is a list of questions to consider and the last one suggests people imagine an animal in their life for the next 10 years or more. If not, animals with shorter life spans ought to be considered instead. I was horrified to see rabbits on that list. How erroneous—rabbits easily live 10 to 12 years with proper care.

Rabbits are high-maintenance pets, requiring space, roomy cages, special foods, veterinary care, not to mention attention, toys and love, just like a dog or cat. If someone wishes a pet, but cannot cope with high maintenance or lots of needs, they should become fully educated before committing to another species.

#### Ryan Jo Summers, North Carolina

# **Airlines may ease travel**

In the Spring 2015 issue of **Momentum**, Chris Whiting wrote in a letter called "No-fly zone," about the <u>difficulty of air travel when one has disabilities</u>. I empathize with Whiting. Because of MS, I also use a wheelchair and require an aisle chair to get on and off an airplane. But I urge Whiting and others not to give up on air travel. While it may no longer be fun, air travel is much easier if you take advantage of the disability services offered by the airlines.

Because I live in Denver where United Airlines has a major hub, I usually fly on that airline and call an 800 number to use the services of the United Airlines Reservations Disability Desk. I like having a live conversation with a knowledgeable employee who can make seat assignments that address my needs, and arrange for transportation within the airports.

Though I often make my own initial reservations on the Internet, I sometimes opt to pay a small fee to handle the whole process, including reservations, through the Disability Desk. I suggest checking to see if your airline offers a similar service, and making reservations six weeks in advance of your travel date so that you have a good choice of seats.

Mary Mullarkey, Colorado