

My MS journal



The list of things I can't do has grown with time. But so has the list of things I can.

by Jane Markey



Jane Markey, who lives with MS, enjoys playing card games with her grandchildren. Photo by Dave Moser

I was born on Feb. 27, 1957. I was diagnosed with multiple sclerosis when I was 30 years old. I have a daughter, Kristi, who was only 2 years old, and a son, Michael, who was 4 years old, at the time.

Let me begin at the beginning. The year was 1987.

One day, I noticed that when I bent my head down, my hands would tingle.

I lost my balance on the last step of the basement stairs and fell. I went to the doctor, who ordered an MRI. When the results came back, he told me I had multiple sclerosis. The news sent me into a crying frenzy. I knew nothing about MS. I thought I was going to die in a short time.

I made an appointment with a neurologist, who described some of the things that probably would happen as time went by. I didn't want to think about it.

I was sure those things weren't going to happen to me.

Two years after my diagnosis, my husband, Michael, and I participated in a walkathon for MS. About halfway through, I realized I couldn't make the rest of the walk. MS was rearing its ugly head.

Here is a list of things I can no longer do:

- Walk
- Run
- Mow the lawn
- Go anywhere without my chair
- Pick up a piece of paper from the floor without the help of my "grabber" tool
- Get anything from the kitchen cabinets
- Get anything above the bottom shelf in the refrigerator
- Stand and take a shower
- Use the bathroom quickly. I have to self-catheterize three times a day.
- Get in and out of the car by myself
- Sometimes, take off my coat by myself
- Sometimes, get off the toilet by myself
- Sometimes, get out of the shower chair and into my wheelchair
- Sometimes, get up from the floor
- Sometimes, get into or out of bed by myself
- Shop for food
- Cook food
- Wash dishes without leaning over from my chair to reach into the sink
- Hang up a new roll of paper towels
- Walk on the beach
- Garden
- Go up any steps
- Go up into the attic in our house

- Hang or retrieve things from a closet
- Change my bed
- Get into and out of the pool from my chair without help
- Pick up anything heavier than a quart
- Open bottles without the use of a rubber band around the cap

We still led active lives. We went white-water rafting, we skied, we played tennis and racquetball. But as time went on, I couldn't do as much. My legs kept giving me trouble. I began walking with a cane. And I was running out of reasons for why I couldn't do the things I used to be able to do. I could no longer blame it on being tired or out of shape.



Jane Markey (left) goes on “walks” with her husband, Michael, and neighbor, Genie.

Photo by Dave Moser

Believe it or not, I loved cutting the grass. But even that became a challenge. For some reason, I couldn't pull the cord to start the mower.

My neurologist told me my MS could affect more than just my legs. I started swimming, which did help with my legs.

After I “graduated” from a cane to a walker, I had to give up going to the pool because it was too hard for me to get around. The stairs in the house became impossible to navigate. I had to stop driving. I began to have muscle spasms in my feet and calves.

Eventually, we moved into a ranch house with no steps. And we built a pool in the backyard. I used it nearly every day. After being in the pool, I noticed so much improvement in my legs.

Here's a list of the positive things in my life:

- I'm home all the time for my kids and grandkids to visit
- I can take "walks" around the neighborhood with my friends and solve all the problems of the world together
- I don't have to go food shopping
- I don't have to cook
- I don't have to wash dishes
- I don't have to put gas in the car
- I don't have to change my bed
- I don't have to hang up the new paper towel roll
- I learned how to use a power chair
- I always have a seat wherever I go
- I can bake cookies because I am level with the oven

And now, to the present. I'm 64 years old. I use a wheelchair all the time. It's been quite a journey, and I've learned a great deal.

MS has taken away my ability to use my legs.

It has reduced my stamina and affected my strength. It's starting to affect my vision. But what it hasn't done and what it will never do is take away my memories or my ability to treasure all the good things in my life.

MS is an absolutely horrible incurable disease. But even though I was dealt a bad hand, I'm still in the game. Don't deal me out!

I'm not going down without a fight. So hold on to your hat.

Jane Markey lives in Erdenheim, Pennsylvania, with her husband, Michael.