

The Five Worst Things I Have Done Since Being Diagnosed with MS



Although I am a relatively smart person, I can admit to having done some pretty dumb things in my life. A lot of the dumbest things came after finding out I had MS. I thought if I listed the top five, it might save someone from repeating my blunders.

MISTAKE #1: Not immediately making long-term financial plans.

I was eight weeks into a brand-new job in 2005 when I was hospitalized with transverse myelitis, which was followed by a diagnosis of MS. I should have looked into disability right away, even if I wasn't ready. I should have learned everything I could have about it.

Instead, I went back to work way too soon and focused on keeping my job instead of maintaining my health.

Despite worsening symptoms that were seriously compromising my mobility and function, I kept pursuing a high-stress career that I was both good at and enjoyed. I ignored the handwriting on the wall regarding my own future.

After two frantic years of working 12-hour days, being on call 24/7, determined to prove that MS would not impact my performance, my position was eliminated and I was out of work. Before finding a new job had never been a problem. But things were complicated now. I couldn't "pass" any more. Now I needed assistive devices, a cane or a walker or more frequently, a wheelchair, to get around. Huge red flag for hiring managers, although, of

course, there is almost no way to prove that.

Two years have passed. Realistically, I am unlikely to ever return to the work force. I am just too sick. I have finally applied for disability, now that my savings are gone and I am in dire financial straits.

MISTAKE #2: Not immediately looking into more accessible housing.

I adore my cozy, 1930s seashore home. It is my dream house. I bought it completely on my own, with no help from anyone, and I have been inordinately proud of it. When we moved in I pulled up ratty old carpet, painted, plastered, fixed, planted, you name it. It is a charming place, full of sunshine and color, where guests settle in and are reluctant to leave because it is so comfy.

I used to be able to blow through the house in an hour, vacuuming, dusting, mopping. While running a few loads of laundry. While setting the sprinkler out for the garden. While dragging garbage out to the garage.

I never anticipated that one day it would take monumental effort to get up the three small steps from the back door to the kitchen. I can no longer do stairs. Or clean the house. Or dig in the garden. Or paint or do any of the things I so reveled in when I bought my house. I, quite simply, cannot take care of it anymore.

If I had made plans early on to move to a smaller home or apartment, one that would be easy to clean and could accommodate my wheelchair, my life would be so much simpler. Yes, I will miss my house and mourn it forever. But the stress of trying to maintain it is sucking the life out of me. And now that the market is horrendous, I will be lucky to get any equity out of it at all.

MISTAKE #3: Not having a frank discussion with my children about my illness in the beginning.

I have four grown children. They are good people with good hearts and I know they love me. But they are really struggling with accepting the harsh reality of how sick I am. I have done both them and myself a disservice by not forcing us all in the beginning to sit down and talk about what MS is, what might happen and what we were going to do about it. I have always been The One In Charge, strong, bossy, doing it all. My husband died when the kids were little and I have misguidedly tried to shield them from pain ever since. By pretending I was fine, by acting as though there was nothing wrong, what I've done has caused even more pain.

So do whatever you have to in order to get your family on the same page and to an understanding of the potential progression of the disease. You might never get to a really bad

place, but being prepared **together** is so important.

MISTAKE #4: Not taking people up on their offers to help.

My amazing friends and my wonderful sister have stood by me for decades through sorrow and joy. And through MS. They were there for me from that first hospitalization. Always, always, always offering help. “What can I do?” they would ask. And what have I replied? “Oh, nothing, I’m good.” I have said this when I am up to my eyeballs in laundry, dishes and housework that was getting harder and harder for me to do.

It has taken me years to finally admit I need help. And lots of it. I am incredibly lucky that everyone is still around offering, because those offers do tend to fade as time goes on and people tire of asking when they are repeatedly turned away.

MISTAKE #5: Not taking care of myself.

I found out I had MS. Did I start eating really wholesome food? Did I do whatever exercise plan fit my abilities? Did I take my myriad of medications regularly and carefully? Did I rest and avoid stress as much as possible? Did I make sure I got plenty of sunshine and fresh air? Did I force myself to get out and socialize so I wouldn’t get depressed?

No. No, no, no, no and no.

I kept working incredibly stressful jobs and hours. I did not focus on nutrition. I swam for a while, until I broke my shoulder. But when I couldn’t swim any more, I did not look for an alternate way of staying fit. I avoided friends and stayed in my room, in my bed, with the shades drawn. Medication?!? Tuh, (I spit on the floor), I don’t need no stinkin’ medication.

That is how you spell D. E. N. I. A. L. With some stupidity and stubbornness thrown in. Yeah, really helpful coping mechanisms.

BOTTOM LINE: You don’t need to panic, but do yourself a favor and make plans. You might never need to use them, but get your safety nets in place. My denial has cost me dearly.

Editor’s Note: For additional information and resources – including SSDI, accessible housing, talking to you children about MS – call an MS Navigator at 1-800-344-4867.