

The still spot



Caring for a partner with MS can bring up a torrent of difficult feelings, but one woman finds a way to experience a moment of peace.

by Judy Stegman

5 a.m. Brilliant light shatters the predawn darkness as my husband Mark snaps on a bedside lamp. Groaning inwardly, I burrow a little deeper under the warm comforter, delaying the inevitable for a few precious moments. Mark gets more insistent, asking me to get up, and I fling back the covers with angry impatience.

Mark was diagnosed with multiple sclerosis nearly 18 years ago and presently uses a wheelchair. Recently, his physiologic changes have pushed us to the foreign land of Texas catheters. But his systemic weakness prevents him from making the necessary delicate movements for successful use. As a result, I have become the twice-daily Expert Bladder Manager. After three months of frustrating trial-and-error, we've finally found a tentative routine of sanity and stability. However, what I didn't foresee was the relentless morning-and-night grind on my time and energy, laced with ragged strands of sleep deprivation and resentment.

I swing Mark's legs off of the bed to drain the urine bag. This routine is familiar; words are unnecessary. The learning curve was tensely volatile, and silence now defines our neutral zone. Kneeling on the floor, threading Mark's jeans over his feet, I have a continuous litany in my head: "I hate this. This sucks. I am SO tired. God, I just sat in a wet spot. This is so gross. I hate this. This sucks."

These barbed wire thoughts endlessly loop. Circling and binding. Constricting like a tightly clenched fist. A sudden insight electrifies. I potentially face years of 5 a.m. awakenings. How will I ever cope? If my thoughts are this caustic after three months, where will I be in three years? What can I do to survive? My frustration roars. My breath expels with explosive resignation, completely emptying my lungs.

Counting to 10, I slowly refill my lungs. At the top, my mind pauses. I discover a moment of stillness, adjacent to the anger. As I begin another breath, I ride the expansion. Reaching fullness, I seek that small pool of quiet. It is still there! Experimentally, I step into this tiny lake and expand its boundaries. With the next few breaths, I play with stepping forward and back, feeling the movement between anger and impartiality, recognizing the difference.

Stay safe

Even in the most loving families, mounting frustration and anger can sometimes erupt in verbal or physical abuse, particularly in the face of overwhelming demands and equally overwhelming fatigue. Visit nationalMSSociety.org/tension to learn ways to reduce tension and nationalMSSociety.org/abuse for tips to keep your relationships respectful and safe.

Turning back to Mark, something has shifted. Stepping out of my head and into my body has dulled the edge of my anger. I roll his sock onto his foot and a toe catches. Damn. I want to jerk the dang sock back in place. Why the hell am I here?

Counting to 10, my inhale begins. Stalling at the top, I observe. The stillness is still here, and a spark of well-being flares in this neutral zone, independent of my surroundings. Each accumulative breath adds fresh edges to my intellectual presence. I remember why I am here: Because of my love for this man needing my help in ways I'd never imagined, and my strong commitment to nurturing him and myself in encouraging ways. My anger is still here, too, and it diffuses into an enlarging pool of mental alertness, physical calm and renewed purpose.

Taking deliberate breaths disrupts the routine chant of anger, and my mind grows more relaxed and soothingly expansive. The world comes into focus and I am, once again, surrounded by the circle of predawn lamplight, finishing the task at hand. The clenched anger-fist has noticeably softened, and I appreciate the simple pleasure of established ritual.

Mark rolls off toward the kitchen coffee pot, and I return to bed. Snuggling cozily under the comforter, I am astonished to be in this state of relaxed ease instead of customary anger.

Remember how this feels, I coach myself. If I can do this just ONE time, surely I can do this again. Sleep tugs, and my sweet thoughts swirl and dance, lulling me with the exciting promise of sustainability. Sighing, I drift with deep contentment to the new music in my head.

Judy Stegman lives in Littleton, Colo., with her two daughters and her husband Mark, who was diagnosed with MS in 1996.

Visit nationalMSSociety.org/carepartners for a wealth of caregiving resources.

We want to hear your unique viewpoint on MS. Submit your story to editor@mss.org.