

Ms. Dale Writes

CAREGIVER CAROUSEL

Caregivers know about the carousel. On a lacquered pony, you ride up (good days) and you ride down (bad days) but the music never stops. There's no choreography. No graceful dismount. Friends, relatives, neighbors stand as spectators. Like neon ribbons their sympathetic faces smear, merge then reappear as you circle in and out of their line of sight. Ignorant. Inexperienced. They have no idea. They see no rotating platform. They cannot hear the notes, feel the rhythm.

Rich and I have been married for over twenty-five years. We share a common history, full of intriguing moments and laughable characters. I have loved him and his size 14 feet ever since he wore blue work shirts and pounded steel for a living. That's him sitting on the wooden bench, the kiddy seat. He's too weak to stay in a saddle any more.

Sometimes, I sit with him. We hold hands and comment on the events of our shared world in a comfortable, if not weary, state of denial. Like when we sit in our deck chairs under the magnolia tree out back, complimenting each other on the excellent quality of our sweet basil and oregano. We go on "hummingbird watch" there, laughing at Red, our resident hummer as he chases interlopers around the abelia and over the butterfly bush. Or, like when I crawl into his, what use to be our, bed to spread my body up against his cold, blanket-wrapped limbs, too fragile for hugs and squeezes like in the old days. We treasure the closeness, the whispered tenderness.

Most of the time, though, I'm up on the horse by myself, jousting medical giants and manipulating all things mundane. "Advocate" has become my middle name. Although we still discuss medical treatment options together, I have become the drawer of pictures, the repeater of words, the rephraser of sentences. Chemo-brain. Every food, clothing, transportation decision I make alone or with just-enough explanation to assure cooperation if not agreement. I've given up grasping for the brass ring. There are no more cures. My sweetheart has become my little boy, on his way to becoming my baby.

On bad days, my wooden horse rides down. There are constipation or pain issues. Oblivious to food or surroundings he sits for hours; claims he's reading. Attempts at normalcy end in crisis. The smell of restaurant food drives him to nausea. His parchment skin tears and bleeds as he brushes an unfamiliar wall. His left foot drags, too weak to make a step. On good days, he can drive himself to acupuncture and come back with his old smile. I ride my pony high.

The emotional merry-go-round continues, spinning smaller, constricted by tempo, a constant din and I cannot get off. Despite well-meaning bystanders, the calliope in their midst is playing for two. I pray for an end, a smooth landing for us both, although I can't imagine what that would be. Not until the music stops.

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