



By Caryn Sullivan

ON A THREE-LEGGED WALK

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I was walking with an old friend recently when the conversation turned to the challenges we both faced in our households. I had angst about what the future holds for my teenage son with autism spectrum disorder (ASD). She was worried about the future with her mother, who is in the early stages of dementia or Alzheimer's; the diagnosis is still unclear. For years, she'd heard about how my son's impulsive behavior has kept me on edge in a way her typically developing children's behavior has not.

Until that walk, I don't know that my friend was able to comprehend what I've dealt with. But as she talked about how variable her mother's behavior has become, how she goes in and out of lucidity, and how she needs so much more care than before, there was an aha moment. Almost simultaneously, we recognized how similar our challenges are now that her mother has begun to slip away, requiring an unprecedented level of supervision.

While she had new insight into my journey, I had a presentiment about hers. For, years ago, Alzheimer's made a stealth entrance into my grandfather's life, stealing his dignity, his sharp mind and his health. Although family gave me regular updates about his decline, I was totally unprepared when I visited him in the Florida nursing home where he spent his final days.

My grandmother, who had seen him wither away, couldn't understand why I didn't recognize the unshaven little guy slumped in the wheelchair as Grandpop, just as he didn't recognize me as his eldest granddaughter. I'd gone to visit a big, strong man who was known for his bear hugs, jokes and bellowing voice. Instead, I was greeted by an unrecognizable shadow. It was heartbreaking to see what had happened to him in the twilight of his life.

As my friend and I walked and talked, I thought about the saying that you can't really understand another's journey until you've walked in her shoes. Our experiences were not so similar that we were wearing each other's shoes that day. It seemed more like I was taking a three-legged walk, one leg advancing independently and the other tethered to hers by our new insight. As heavy as the conversation was, it felt good to finally have my struggles understood as well as to empathize with what she was going through.

I've thought about our conversation many times since because it underscored the parallels between ASD and Alzheimer's, which I find both intriguing and worrisome. The incidence of both conditions is increasing at an alarming rate.

Although ASD strikes at the outset of life, while Alzheimer's intrudes at the sunset, both conditions have a dramatic impact on families. There can be embarrassing behaviors and awkward hygiene issues to deal with. There is a difficult balancing act of letting one live his life while protecting him from dangers he may not appreciate. Both conditions

can involve complicated financial considerations such as whether to care for the loved one at home, often at great expense, or to opt for a residential living option — an emotional and costly move, as well.

More than anything, though, there is a lot of grief. With ASD, there is the loss of the dream of what life could have been that results when a child's normal development is mysteriously derailed. With Alzheimer's there are the loss of adult companionship and the pain of helplessly watching a loved one's life unravel. Both conditions can require extraordinary sacrifices of family and friends to meet the needs of the one beset by the condition, with little or none of the reciprocity inherent in most relationships.

As to my friend, I can look into my crystal ball and see what likely awaits her family if Alzheimer's is the diagnosis. I know how the roles will be reversed and her devoted mother will be cared for by those she raised to be good mothers and fathers themselves.

I know that this family will face difficult decisions about when to pull her car keys, when to leave her alone and when to supervise her in the kitchen, and I'm sad for them. As to my son, while there is no crystal ball, I know we will face many difficult decisions as well. But at least I know that when the need arises, I have a cherished friend with new insight who likes to take three-legged walks.

Caryn Sullivan is a Minnesota attorney and writer. Her column appears occasionally on these pages. Her essay, "Dancing with Despair," is featured in "Special Gifts: Women Writers on the Heartache, the Happiness, and the Hope of Raising a Special Needs Child" (Wyatt-Mackenzie, July 2007). Her email address is carynsullivan@comcast.net.