



CAREGIVER'S PERSPECTIVE

MaryAnne Sterling, CEA

Adult Daughters: Our Nation's Front Lines of Caregiving in the Era of Alzheimer's

In honor of A Day Without a Woman, my friends at Daughters Unite quoted one of my frequent go-to sayings: "If adult daughters went on strike tomorrow, our health care system would collapse." It's time I explained why I say this so often.

I spent more than 20 years shepherding my aging parents through the health care and social services systems. From the beginning, I found myself in an adversarial relationship with both of these siloed systems. Why? Because I had information. I knew my parents better than the health care system knew them. I was a caregiver and translator, who just happened to be their daughter.

Times have changed for adult daughters. In the era of Alzheimer's, we are desperately trying to deal with a disease we don't understand, one that our best scientists and neurologists are still struggling to grasp. There are no good treatments. There is no cure. According to the latest numbers from the Alzheimer's Association, more than 5 million Americans are living with Alzheimer's, and another 15 million family caregivers are on the front lines caring for them. A growing number of these caregivers are adult daughters. According to some sources, more than one-third of dementia caregivers are daughters. I would argue, however, that we don't have reliable numbers to quantify how many adult daughters are participating in caregiving activities. Why? To the outside world, we are invisible.

What We Do

Being a parent to your kids is one thing. Being a parent to your parents is a completely different beast, and yet adult daughters are expected to assume this role with no preparation, no training, and no complaints. Some of us did not have picture-perfect childhoods with the Cleavers, so we end up caring for difficult parents while we struggle with our own emotional baggage.

Alzheimer's and other forms of dementia present unique challenges to family caregivers. As the disease progresses, the person afflicted may become combative, wander away from home, or refuse to bathe. They may no longer recognize their family members. They often repeat the same story or ask the same question hundreds of times. Eventually, they can't be left alone anymore without tremendous risks, which may include wandering, falling, leaving the stove on, or other life-threatening situations. For many, the disease is present for a decade or more. For adult daughters, this equates to a permanent change of life plans. More on that later.

In addition, we are increasingly asked to provide care that was once reserved for nurses and other medical

professionals — wound care, infusions, colostomy care — and I have watched my fellow caregivers struggle

to manage the blood sugar of a patient who no longer understands why a needle is pricking their finger three

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Experience Breeds Knowledge

Adult daughters are the information hard drives of health care. We have to assimilate knowledge that spans numerous domains in order to support our loved ones. This includes medical, insurance, legal, and social services information. We are advocates, care coordinators, medical record keepers, medical decision makers, insurance navigators, medication administrators, and more. We frequently have to speak on behalf of our parent(s) who may have lost the ability to recite their medication list or describe the circumstances that led to a fall or illness. We are well-versed in how Alzheimer's has affected our parent. The care we provide and decisions we make often keep our loved ones out of the emergency department, and integrating caregivers into the discharge process significantly reduces patient readmissions, according to a new study [*J Am Geriatr Soc* doi:10.1111/jgs.14873].

Overwhelming and Costly

The impact of Alzheimer's caregiving on adult daughters is often devastating. What you don't see are the consequences. The price of caring for someone with Alzheimer's or other forms of dementia is high:

1. Mom and/or dad move into your home. Your relationship with your spouse and children changes. You don't have time for them anymore. Nothing prepares you for the stress.

2. Your siblings are in denial or don't agree with your care decisions. This results in endless arguments and the bulk of the caregiving burden falling on you.
3. Friends and family eventually disappear as the disease progresses and caregiving consumes more of your time. Your ability to get away for lunch with friends or enjoy a movie or shop is non-existent.
4. Your health suffers. You used to go to the gym, but that falls off the priority list. You aren't eating as healthfully as you used to. You realize that you are depressed, but you don't want to admit it. You soldier on. This eventually translates into chronic health conditions of your own.
5. You leave the workforce, unable to balance complex caregiving and a career. This has financial implications that last for years: dwindling bank accounts, disappearing retirement accounts, and decreased Social Security benefits.

Why We Can't Get Help

In reality, there is no help. Services that family caregivers need — home health or companion care, affordable housing, transportation — are often not available in their community or simply not affordable. Medicare does not cover custodial home health services related to Alzheimer's. But if your parent breaks their hip, you're in luck (snarky comment intended). If you are fortunate enough to be able

to afford home health or companion care, you will struggle mightily to find health care workers trained in dementia care.

The health care system is tone-deaf to the sacrifices of adult daughters. A diagnosis of Alzheimer's does not come with an instruction manual and few medical professionals are trained in Alzheimer's care and the complexities of caregiving. We are expected to find support and resources on our own. Ironically, we are expected to stay 24/7 with our parent when they land in the hospital, with excuses of "not enough staff" frequently lobbed in our direction. So we set up camp and try to prevent mom or dad from pulling out IVs, falling, or other calamity. We suddenly become useful to a system that frequently ignores us.

The Bottom Line

Adult daughters are overwhelmed when it comes to Alzheimer's caregiving. The health care system, policymakers, advocacy groups, communities, and faith-based organizations need to work with us to create real solutions. The expectation that adult daughters will automatically assume the role of caregiver for their aging parents with Alzheimer's is not a solution.

We need a national focus on training. I have encountered a lack of basic dementia knowledge across all levels of health professionals. Clinicians and health care workers need targeted training in this disease to be effective care providers.

We need care options. Right now, we have two choices: keep our parents at home with no support or spend down and put them in a nursing home under Medicaid. We need home- and community-based services that are practical and affordable.

We need mobilization. This is an epidemic and we need to respond to it as such. The federal government, states, and local communities need to mobilize resources to support adult daughters who are on the front lines.

Imagine if adult daughters simply stopped caregiving for a day. Emergency medical services would be overwhelmed with calls, while emergency departments would quickly fill. All of the institutional knowledge about Alzheimer's care, embedded in adult daughters, would cease to exist while the health care system — unable to care for millions of people who have a disease it doesn't understand and caregiving needs it can't begin to appreciate — crumbled. This article was previously printed in the July 2017 issue of *Caring for the Ages*. DOI: 10.1016/j.carage.2017.06.016

Ms. Sterling is a speaker and educator on family caregiver issues and dementia, and has been featured in *Kiplinger*, *The New York Times*, *USA Today*, and *The Wall Street Journal*. She is chief executive officer of Sterling Health IT Consulting. Follow her on Twitter at @SterlingHIT.

Roam If You Want to: Unlocking Doors for Patients With Dementia

Joanne Kaldy

The author of *Dementia Beyond Drugs: Changing the Culture of Care* and *Dementia Beyond Disease: Enhancing Well-Being*, G. Allen Power, MD, posted a photo on social media of a door in a dementia unit decorated to resemble the corner of a lovely room with a bookcase and flowers in a vase. At first glance, it is visually appealing. But the truth is, said Dr. Power, it is still a door. Instead of disguising or locking doors to keep people from leaving, "We need to figure out why they want to leave, and we need to



G. Allen Power

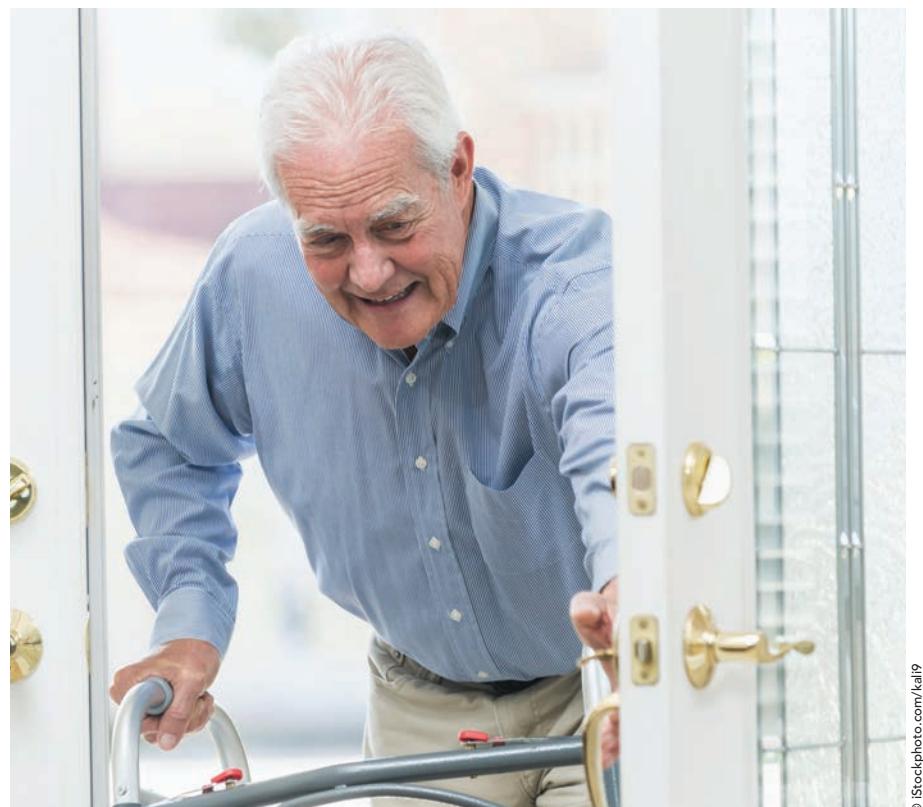
think about the needs we're not meeting," he said.

Even though facilities have embraced person-centered care and made efforts to address residents' wishes, habits, and preferences, concerns about safety — while valid — often override personal choice. "We need to do a better job of balancing safety and resident rights. Too often, we automatically default to lockdowns, especially for residents with dementia," Dr. Power told *Caring*. "As long as we do this, we'll never find the nuanced ways to get past this."

It is common to look at the "bad side of risk," that is, the worst-case scenarios of the possible implications of an action such as leaving doors unlocked. "We don't consider the risk of what potential damage the locked doors can do. Until we look at both sides, we're not doing all we can do for our residents," said Dr. Power.

The Fallacy of Falls

Dr. Power shared a story he heard about family members seeking an assisted living facility for their mother.



Ensuring residents' needs are met so they don't feel the urge to escape creates a safe environment that allows them to walk freely or go outside.