



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.

Caring for Consumers

Making Long-Term Care a Family Affair

Joanne Kaldy, *Caring* contributing writer and daughter of a nursing home resident, and *Caring* editor in chief Karl Steinberg, MD, CMD, talk about how families can help ease loved ones into nursing home life.

It's never easy to move a loved one into a nursing home, but there is much families can do to make this a smooth transition and a positive experience for everyone.

Communication is key, and this can start at admission. Make sure staff have copies of your loved one's key documents such as an advance directive or living will, Physician Order for Life-Sustaining Treatment paradigm (POLST, MOLST, POST, COLST and others) form, and medication list. Let them know if your loved one has a designated decision-maker, who should be contacted when there are issues or problems, and what means of communication is best. If your loved one doesn't have an advance directive on admission, staff can help them complete one.

Every patient must have an attending physician to oversee their care. If the physician your loved one saw in the community can't or won't follow them into the facility, you and your loved one can choose an attending physician. The facility can help identify someone to fill this role. You should help this practitioner to get to know your loved one.

Find out who the facility medical director is. This person is a physician and the facility's clinical leader who works closely with both the administrative and care staffs. By law, every facility must have a medical director. Most medical directors are in the facility frequently and can serve as the attending physician for otherwise unassigned residents.

Shortly after admission, you will be asked to participate in a care planning conference to discuss your loved one's care. This is an opportunity to make sure staff and family are on the same page. You can help staff get to know your loved one during this meeting by discussing things such as foods they like or dislike, fears or phobias, and family dynamics that might arise.

You will discuss goals during this meeting. For instance, do you hope to get your loved one into an independent living situation or just well enough to go to assisted living? Although everyone hopes for the best, be prepared to identify realistic goals and expectations, based on the person's condition and prognosis. The facility will revisit goals with you over time, especially if your loved one has an acute change such as a fracture, stroke, or heart attack.

As your loved one settles in, bring in clothing, blankets, photos, or other mementos; arrange for food they enjoy and activities they like. The facility wants your loved one to be safe and comfortable; if there is a problem (such as mom has a bruise or dad is agitated), talk to staff right away. Talk to the physician or other practitioner before giving your loved one any over-the-counter medications or herbal supplements, or food from outside the facility.

Questions to Ask Your Practitioner

- What kind of communication will I have with staff?
- What can I do to make my loved one as happy and comfortable as possible?
- What do I do if I report a problem and it isn't addressed/resolved?

What You Can Do

- Visit as much as possible.
- Work with staff to involve your loved one in activities or events they will enjoy.
- Help staff get to know your loved one as a person.
- Report problems/concerns promptly.

For More Information

- How to Look Out for a Relative in a Nursing Home: <http://bit.ly/2rx8lr8>
- When Short-Term Rehab Turns into a Long-Term Stay: <http://bit.ly/2sBeexM>

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 parent who no longer understands why a needle is pricking their finger three times a day and becomes combative every time.

Experience Breeds Knowledge

Adult daughters are the information hard drives of health care. We have to assimilate knowledge that spans numerous



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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.

The federal government, states, and local communities need to mobilize resources to support adult daughters who are on the front lines.

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. 

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.

Call for Abstracts

2018 ANNUAL CONFERENCE

AMDA – THE SOCIETY FOR POST-ACUTE AND LONG-TERM CARE MEDICINE

MARCH 22-25, 2018

Gaylord Texan Resort & Convention Center · Grapevine, TX



Submit online at <https://amda2018.abstractcentral.com>.

The Annual Conference Program Planning Subcommittee invites you to submit abstract proposals for AMDA – The Society for Post-Acute and Long-Term Care Medicine Annual Conference 2018, March 22-25, 2018 in Grapevine, Texas.

TARGET AUDIENCE

The program is designed for medical directors, attending physicians, nurses, administrators, consultant pharmacists and other professionals practicing in the post-acute and long-term care (PA/LTC) continuum. Medical students, interns, residents and fellows planning a career in geriatrics are also encouraged to attend.

SUGGESTED TOPICS

The Society welcomes submissions on all topics pertinent to PA/LTC medicine and medical direction. Emerging clinical information, best practices in management and medical direction, research, innovation in PA/LTC, and updates on approaches to regulatory compliance, are areas of interest. The Society also seeks skill-based proposals that incorporate interactive learning strategies and provide attendees with resources to implement upon return to practice.

HOW TO SUBMIT

To submit an oral proposal or abstract for the 2018 Annual Conference or for more information, please go to <https://amda2018.abstractcentral.com>. All abstracts must be submitted via the abstract submission site.

QUESTIONS?

Contact the Society's Professional Development/Meetings Department at education@paltc.org.

APRIL 25, 2017

Abstract Submission Site Opens

JULY 12, 2017

Deadline for Oral Presentation Submissions

OCTOBER 26, 2017

Deadline for Poster Abstract Submissions



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