



## CAREGIVER'S PERSPECTIVE

MaryAnne Sterling, CEA

### The Most Important Mental Health Issue You've Never Heard Of

I am the person least likely to talk about emotions — I have bottled up a lifetime's worth. As a family caregiver for over 20 years, I have been on a seemingly endless roller coaster of emotional stress that has affected me in ways I never imagined. And I suspect I am not alone.

The wisdom of hindsight has convinced me that it's time to bring this topic out from behind the curtain and make it part of a broader dialogue: the impact of caregiving on the caregiver. The specifics may surprise you.

Let's start with guilt. The caregiving journey is driven by guilt, which comes in many shapes and sizes. As an adult daughter and only child, I had no one to share the experience with. I had to make all the decisions and live with the consequences. First, there's the guilt of feeling like your life is being pulled out from under you and you just want it back. Then you feel guilty every time

you are exhausted and raise your voice in anger to the person you care for. Next, when you must place your loved one in a facility, the guilt is overwhelming — even when you know you are totally exhausted, broke, and have no other choice. Finally, the guilt becomes crushing when you must decide to stop life-saving measures like antibiotics — even though you are respecting your loved one's wishes.

Next in line are frustration and anger, which lead to anxiety. Nothing prepares you for the daunting task of dealing with our fragmented health care system, especially when it comes to elder care. As a caregiver, you become the middleman who has to navigate, communicate, and problem solve. You become the care coordinator and the insurance intermediary. You track down services, interview home health agencies or nursing homes, navigate the Medicaid spend-down,

accompany family members to medical appointments, research health conditions and diagnoses, analyze finances, pick up medications, arrange appointments ... and make endless phone calls.

Caregiving is a second full-time job, in which frustration and anger are unavoidable:

- Health care providers answer their phones from 8:30 to 5:00, Monday through Friday, with 1.5 hours off for lunch. Meanwhile, you work during those same hours, so you must make the calls to them from the restroom, or during your (late) lunch hour, or after taking time off for the purpose.
- When you go to pick up Mom's CT scan results, you discover the imaging center won't give them to you because of HIPAA. So you have to load your mobility-challenged mother in the car and make a second trip to the imaging center to retrieve the test results and DVD with the images.
- The home health care worker who has been assigned to Dad was not trained in Alzheimer's care, and she has no idea what to do when he becomes agitated.
- The doctor's office miscoded a medical test for Mom, so insurance won't cover it. But you don't find this out until you already have been on the phone with Medicare for over an hour. Then you have to call the doctor's office to relay the information Medicare gave you and sort out the problem.
- The pharmacy called to say that Dad's prescription is ready for pick-up. But when you get to the pharmacy, they tell you that his medication is out of stock. Because Dad is completely out of his medicine, you must find another pharmacy to get the prescription filled.
- The only appointment time available for Mom's doctor visit is 11:00 a.m. on Monday, so you have no choice but to take another day off work to accompany her and ask questions.
- Your boss reminds you that you have used all your vacation time and any additional days you take off will be unpaid.
- Mom now has diabetes and needs insulin injections. You are not comfortable testing her blood sugar or giving her shots, but no one at the doctor's office has time to train you.
- You need additional caregiving support, but you can't find affordable services in your community.



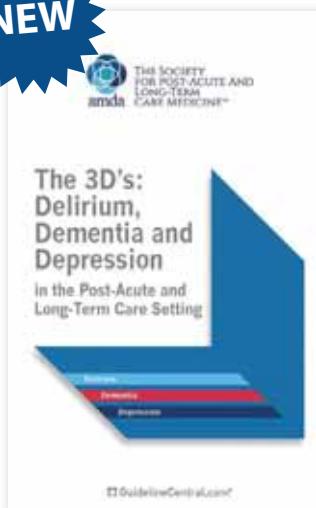
Caregiving is an endless roller coaster of emotional stress.

- Dad has fallen and is taken to the emergency department. When he is discharged seven hours later with a cast on his leg, you have nobody who can lift him or get him from his bed to the bathroom once he is home. Home health will come "evaluate" him in a few days, but what are you supposed to do until then?
  - Surprise! You've discovered Medicare does not cover Alzheimer's care in the home, nor does it cover nursing home care. Now you have to manage a Medicaid spend-down in order to get more care for Dad.
  - Now you discover Dad doesn't qualify for Medicaid because his income is \$250/month over the limit.
  - Your marriage is falling apart due to the strain of caregiving.
- Finally, abject fear also plays a key role, leading to more anxiety. What are caregivers fearful of? Common scenarios include:
- Being unable to afford care as the health care needs of your parents increase.
  - Losing your job because of caregiving responsibilities and the time off required to deal with doctors' appointments, transitions of care, emergency department visits, legal issues, and more.
  - Living with the constant fear that your dad with Alzheimer's will wander or fall because you can't find/afford a caregiver and must leave him alone at home.
  - Expecting retribution by nursing home or rehabilitation facility staff because you complained about the quality of care your mom is receiving.

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## Mental Health

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- Receiving the 3:00 a.m. phone call after your mom falls getting out of bed to use the bathroom.
- Not having time to go to the doctor or have tests to find out if the lump you discovered is breast cancer.
- Fearing you'll get Alzheimer's yourself because both of your parents have it.

All of this leads to emotional and psychological strain that can linger for years. My friend Meryl Comer often speaks of the “heightened state of alert” we remain on — even after caregiving is over. For many of us, this is a form of posttraumatic stress disorder, as described by Judith Graham in a *New York Times* article (“For Some Caregivers, the Trauma Lingers,” Jan. 30, 2013; <https://nyti.ms/2NOJUvw>) and more recently in a blog post by Maria Deneau of the Women's Alzheimer's Movement

(“Alzheimer's Caregiver Burnout,” Oct. 15, 2018; <http://bit.ly/2Jy4ryM>), based on her own caregiving experience.

In my own situation, years would pass without anyone asking how caregiving was impacting my health and well-being. It never occurred to my family, friends, and colleagues that the cumulative effects of over 20 years of being a one-person care team for my parents took an emotional toll that can scarcely be quantified. One of the most noticeable lingering issues is my brain has been

rewired to expect the phone to ring at 3 a.m. This was the time health care providers typically would call to inform me that my mom had been injured in a fall. Even though my mom died 3 years ago, I am still on high alert, expecting the call to come again.

*Improving the work life of health care providers (which includes family caregivers), enhancing the patient experience, improving population health, and reducing costs comprise the four pillars of the Quadruple Aim.*

Our country has begun a serious dialogue about mental health at last, typically in the context of the mass shootings that have become all too common. However, in a country with tens of millions of family caregivers (AARP, “Caregiving in the U.S.,” June 2015; <http://bit.ly/2XxXHLc>), the emotional toll of caregiving also must be acknowledged and addressed. We have been leaving our caregiving warriors behind on the battlefield. 

Ms Sterling was a caregiver and healthcare advocate for her parents for 20+ years. She is a speaker, writer, and educator on the challenges of family caregiving, dementia, person-centered care and technology. She is EVP of Caregiver Experience at [Livpact](https://www.livpact.com). Follow her on Twitter at [@SterlingHIT](https://twitter.com/SterlingHIT).

### EDITOR'S NOTE

The original Triple Aim of the Institute of Healthcare Improvement (IHI) was to enhance the patient experience, improve population health, and reduce costs. However, the IHI realized a vital component was missing: caregivers. Both professional and family caregivers have reported widespread burnout and dissatisfaction. Caregiver burnout is associated with lower patient satisfaction, reduced health outcomes, and increased costs, all impediments to the Triple Aim. Consequently, we now have the Quadruple Aim, which includes support for caregivers so they can weather the emotional roller coaster of being on the front line of care. We look forward to sharing learning experiences about how best to accomplish this Aim. Tweet your thoughts to *Caring for the Ages* [@Caring4theAges](https://twitter.com/Caring4theAges).

—Richard Stefanacci,  
Coeditor in chief

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