



CAREGIVER'S PERSPECTIVE

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Mobilizing Former Family Caregivers

Many friends and family asked me this inevitable question after I lost my mom last year:

“What are you going to do now? You’ve spent 20 years caring for your parents!”

Both my parents had dementia and other chronic conditions, and I was their health care navigator and pit bull advocate.

Answering this question has been tough. The aftermath of caregiving is not simple. I was compelled to use the skills I had acquired advocating for my parents to make a difference — now I want to mobilize others.

The Journey

Although every caregiver’s journey is different, those who care for their aging parents share many common traits. We accrue enormous amounts of information, including medication, insurance, legal, and disease-specific information.

In addition, we often provide complex medical care. We spend countless hours navigating our fragmented health care and social services systems. Over time, we interact with acute care, post-acute care, long-term care, and sometimes hospice. For most of us, critical information is obtained by sharing experiences and solutions with our social networks, including other family caregivers with similar caregiving experiences. We attain a wealth of knowledge and experience.

We become resilient advocates for our loved ones. Along the way, we discover the limitations of our health care system and learn how to navigate them. We connect the dots with essential services like transportation, Meals on Wheels, and companion care. We fill out the endless paperwork required of hospital visits, including Medicare coverage and Medicaid eligibility, on behalf of our loved ones.

We step in to manage care transitions when the health care system cannot. We interpret complex medical terminology and insurance jargon along the way. We know where processes are broken, causing gaps in support for our families. We become experts in the disease or conditions that impact the person we care for. We decipher, decode, and translate on a daily basis. This makes us incredibly well-positioned to advocate health policy, health care delivery, and medical research, and become trusted advisors in our communities.

The Challenges

Despite our wealth of expertise, we face many challenges that often prevent our voices from being heard and amplified.

The caregiving journey is undervalued by our society. It is expected that adult women will be caregivers — to our children *and* our parents. This expectation does not come with an instruction manual, roadmap, or helping hands. Family caregivers are often physically and mentally exhausted, our lives shattered by the experience. When we become “former” family caregivers, we deal with the emotional, financial, and health implications of caregiving for years after our caregiving journey ends. The myriad impacts of caring for our aging parents have become a silent national crisis.

In addition, family caregivers fail to recognize the magnitude of our lived experience and how important that experience is to the national dialogue on health care transformation. We also have a credibility issue: the perception that family caregivers are uninformed and can’t provide reliable information because we don’t have medical degrees. In reality, our boots-on-the-ground perspective gives us unique insight that most medical professionals, researchers, and policy makers simply don’t have.

Reimagining the Journey

It’s time to reimagine the caregiving journey, empowering former family caregivers to share their valuable information and experiences by taking an active role in health care transformation — from policy to delivery to research. There are many opportunities for collaboration at the national, state, and local levels. Here is what we can do as former family caregivers.

- Participate in health policy discussions and health care delivery transformation. Become part of the discussion at the Society for Participatory Medicine, Right Care Alliance, the Institute for Healthcare Improvement, and the National

Academies of Medicine. Apply to be on a patient/caregiver advisory council at your local hospital or health care system.

- Talk to your elected officials. Tell them your story. Advocate for legislation that matters to you as a caregiver. That legislation may include respite programs, eldercare leave, access to home- and community-based services, tax credits, and a national strategy to address our caregiving crisis.
- Participate in medical research. Get involved with the National Alzheimer’s and Dementia Patient and Caregiver Powered Research Network and amplify your caregiver perspective in Alzheimer’s research. Or learn what other disease-specific Patient Powered Research Networks are doing (they represent many different diseases and conditions). Get involved with the Patient Centered Outcomes Research Institute. Join the dialogue at UsAgainstAlzheimers. Follow these organizations on social media.
- Attend a health care conference. This is a personal pain point of mine: health care conferences and scientific meetings that don’t include patients and family caregivers as partners. These events need to ensure their attendee and speaker lists include us as critical stakeholders. Many early adopters now offer patient and family caregiver scholarships. Some that are already on board include the National Caregiving Conference, the Beryl Institute Patient Experience Conference, Cinderblocks, and Stanford MedicineX. Participate by attending, listening, asking questions, and sharing your experience.
- Be a source of wisdom. Educate your own social circle. Support active caregivers in your community as a coach or advisor.

If you represent a health care system or are a researcher or policy maker, seek out current and former family caregivers. Listen to our experiences and ideas. We are your neighbors, coworkers, family, and friends. We are an army of knowledgeable family caregivers — and all ready to help.



Ms. Sterling is a speaker and educator on family caregiver issues and dementia. She is cofounder of Connected Health Resources and is chief executive officer of Sterling Health IT Consulting. Follow her on Twitter at @SterlingHIT.

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