

A Caregiver's Journey to Transform Senior Care

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INTRODUCTION

I spent 20+ years as my parents' health advocate, care coordinator, healthcare and social services systems navigator, and care transition team. I am an outspoken advocate for families like mine: dealing with aging parents, dementia, multiple chronic conditions, and a broken healthcare system.

I serve as Patient Research Partner and Ambassador for the Patient-Centered Outcomes Research Institute (PCORI), and Advisor for the National Alzheimer's & Dementia Patient & Caregiver-Powered Research Network.

OUR CARE JOURNEY

My mom: A 2-time, 42-yr breast cancer survivor. Dementia and neuropathy led to 7 major falls resulting in 13 broken bones. The last one eventually took her life.

October 28, 2015: Mom broke her ankle at the age of 85. She was bounced from hospital stays to rehab, to assisted living, to nursing home in a staggering 7 care transitions over the next 4.5 months.

Her ankle was the sole focus of treatment; her many other health needs were all but forgotten. And nobody wanted (or knew how) to deal with her dementia.

Mom died on May 3, 2016.



WHAT THEY DIDN'T KNOW...

Many of the tools used in physical therapy and basic patient care, like hoisting straps and bed pans, contributed to multiple *compression fractures* of mom's spine.

Mom was in constant pain. Nobody believed her.



WHAT WENT WRONG?

- **Episodic approach to healthcare rather than whole-person approach.** Treating the broken ankle derailed management of her chronic conditions.
- **One-size-fits-all approach to therapy.** My mom, a frail senior, was expected to participate in aggressive physical therapy. She was labeled "non-compliant" when she could not participate due to acute back pain.
- **Palliative care introduced very late in the journey.** This approach would have served her well during fall/surgery recovery. Instead, she was over-medicated with narcotics which contributed to her cognitive decline.
- **Mismanaged care transitions.** This resulted in family caregiver intervention – in all 7 care transitions.

WHAT CAN WE DO DIFFERENTLY TO ACHIEVE BETTER OUTCOMES?

- **Treat the whole person.** Positive outcomes rely on the patient's psychological well-being, too.
- **Integrate palliative care services.** Make palliative care a normal part of the workflow for senior care.
- **Listen to complaints – they are real.** Seniors with dementia are telling the truth when they say they are in pain. It just might take a little longer to sort out where the pain is located.
- **Train providers on dementia.** Dementia is an epidemic; everyone needs training in dementia care.
- **Improve care transitions.** Transitions of care for complex seniors (many of whom can't advocate for themselves) require communication, coordination, and alignment with family caregivers.
- **Listen to family caregivers.** Adult children have a wealth of information to share – listen to us. We are a critical part of the care team. By the time you meet us, we have typically been on the front lines of caregiving for YEARS.

WE NEED TO ADDRESS...

- Fragmented healthcare system = difficult (sometimes impossible) to navigate
- Medical records = incomplete and difficult to access (paper AND electronic)
- Care and services coordination for seniors = currently non-existent
- Care transitions = critical points of failure
- Healthcare system = unprepared for Alzheimer's & dementia
- Family caregivers = unprepared, untrained, and stuck in the middle

Important Reading:

Participatory Healthcare: A Person-Centered Approach to Healthcare Transformation
Jan Oldenburg, Mary P. Griskewicz (2016)

