Designing Patient-centric Dementia Care: An Expert Care-giver's Perspective

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"I had a patient who used to tell me 'Aging is not for sissies,'" Tammie Easterly recalls. "We used to laugh so much," says the manager of Prescott Valley Assisted Living. "But I understand what he meant. Aging can be hard for people, especially when dementia starts developing and people alternate between lucid moments and dementia episodes."

As a residential assisted living manager, Easterly oversees the care of 10 senior residents in tandem with a team of six other service staff. She is the point of contact for the families of these seniors, and for the overall team of medical providers. It is her job to make sure that her team is professionally trained to provide the best-possible patient care and service – that medications are administered adequately, wounds are tended effectively, and that clients are always safe. Likewise, Easterly

ensures that the families of Prescott Valley Assisted Living are updated to any changes to their loved one's condition, and to work closely with the medical-care teams to provide real-time assessments of residents. Easterly's responsibilities require empathy, endurance, quick thinking, self-control and a thorough understanding of policies, procedures and medications.

But before being a manager, she is first and foremost a caregiver, with more than 20 years' experience. She first started by taking care of her grandmother in her early teenage years. Then, she became a member of the wait staff in an assisted living facility in Scottsdale, before becoming a certified caregiver when she turned 18. Over the years, she has learned to know seniors and how to understand them. She has learned how to care for people with dementia and Alzheimer's, people who suffer from traumatic brain injuries (TIBs), tetraplegics, quadriplegics, people with feeding tubes, tracheotomies, catheters, wounds and more. She has learned what medications can do for her patients, but she has also learned their limits. Through time and careful observation, Easterly has learned the essential difference between treating symptoms and caring for a person.

"When training to become a caregiver, we do a lot of book work, but the actual experience of learning to be a caregiver is very observational," Easterly says. "You must ask yourself: Why are they acting like that? What do they need? If they can't speak, what is their body language telling us? Your focus has to be on their needs in real-time.

"What we do here is to go beyond treating the symptoms; instead, we treat the patient."

The patient. The National Academies of Science, Engineering, and Medicine notes, "Persons living with dementia are unique individuals – with their own values, including concerns related to privacy; needs; and preferences for services, supports, and medical care – the specific goals for and forms of care, services, and supports will depend on the individual."[1]

1 Engineering National Academies of Sciences, and Medicine. "Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward," (Washington, D.C.: The National Academies Press, 2021).

Over her years in senior healthcare, Easterly has developed her own routines and processes in order to more fully and effectively observe and care for incoming residents.

"We need better observational assessments of people with dementia, and in that effort, clinical narratives play a critical role," she says. "Can they stand when going to the bathroom? Do they need support to sit down? Can they put the toothpaste on the toothbrush themselves?" These questions are key to her initial assessment.

When admitting a patient, she conducts a customized observational assessment. For seven days, Easterly compiles detailed notes of behaviors, wounds, sleeping habits, drinking and bathroom patterns. During this week of discovery and assessment, Easterly visits multiple times each day with her newest resident to compile her notes, including their mood, speech, preferences and habits – and how that might differ from visit to visit.

"Doing that allows me to see the person behind their symptoms and lists of medication," she says of her rounds. "I try to create an environment in which they can comfortably feel free to ask questions and share background that will allow me to provide a comfortable and familiar environment for each individual. For women, Easterly asks, do they wear a bra? Do they like wearing one? Do they prefer a sports bra? Once a patient is settled, Easterly focuses on the patient's new surroundings – Do you know which drawers your clothes are in? Where will you put your keepsakes? Do you know where the light switch is?

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"Although these might seem like insignificant details, they make a world of difference for the patients. Knowing a patient's background – their life story – is important to providing quality care and service, but it's just as important to help them understand who they are *now*, because this part of them must be understood, appreciated and celebrated."

Dementia patients often feel disoriented,[2] anxious,[3,4] and depressed[5] – every step taken to ensure a smooth transition matters. Through her seven-day observational assessment, Easterly is able to build a sense of routine and stability for her newcomers. The service plan that comes from her assessments provides her team members with an invaluable map of care, including *who* the patient is, *what* the patient's needs are, *where* they are most comfortable and *when* they may need special attention. Such a game plan is a critical tool in treatment, especially in those times and those cases when a patient may not be lucid. Such detailed notes are excellent clinical narratives that are shared with the patient's medical providers, which in turn allows that team to develop better diagnostics and more customized treatment.

The assessments serve another, important purpose in preventative care. "There is an element of dishonesty that must be understood and recognized," says Easterly. "People will often lie in an attempt to minimize the condition of a patient. Families hide the facts, hospitals hide the circumstances, skilled nursing professionals downplay particular needs, placement agents are not always forthcoming with critical information or complete background accounts."

There is method in the madness. "These patients many times are in the hands of someone – an agency, a hospital, a family – who is, quite simply, looking to get rid of a patient, or to place them quickly," says Easterly. "They might tell us they have someone who is calm, who can shower on their own, can use the bathroom by themselves and need no special assistance at mealtime, and we discover a very different person." In such cases, not only is proper care and treatment initially lost in the disguise – along with critical time – but physical complications such as flight risk, acting out and self-endangerment can obstruct effective treatment.

2 Ladislav Volicer and Ann C. Hurley, "Review Article: Management of Behavioral Symptoms in Progressive Degenerative Dementias," *The Journals of Gerontology: Series A* 58, no. 9 (2003).

3 M. W. B. Silva et al., "Sundown Syndrome and Symptoms of Anxiety and Depression in Hospitalized Elderly," *Dement Neuropsychol* 11, no. 2 (2017).

4 R. J. Riley, S. Burgener, and K. C. Buckwalter, "Anxiety and Stigma in Dementia: A Threat to Aging in Place," *Nurs Clin North Am* 49, no. 2 (2014).

5 Z. D. Gellis, K. P. McClive-Reed, and E. Brown, "Treatments for Depression in Older Persons with Dementia," *Ann Longterm Care* 17, no. 2 (2009).

"It is much more in the patient's interests, and in our ability to serve that person, if we are provided upfront and honestly a proper history and update on the patient's behaviors," Easterly continues. "People who are honest with me, we have great success stories."

Unfortunately, Easterly's observational assessment and clinical narratives, while being a proven best practice for dementia care in residential settings,[6] are far from being the norm. As a result, many patients who display dementia symptoms are unfairly labeled as aggressive and are subsequently prescribed strong doses of sedatives. It doesn't have to be so. "Most of our patients were originally diagnosed with some behavior," she states, adding, "But, after a few weeks, they are calm and follow their daily routine, as they become acquainted and comfortable in their new environment. And, we are often able to work with their medical providers to reduce or completely drop the sedatives."

Dementia patients are further victimized, says Easterly, by hospital care and treatment that fails the disease, thereby failing the patient. "Patients often come back from the hospital with pressure sores, or pneumonia, because their stay was restricted to bed rest, they were kept immobile or restrained. They often come back with bruises because they were strapped down due to lack of staff to sit with the patients. The condition that patients were admitted for was treated, but the whole person was not."

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Easterly continues, "If we are not diligent in our assessment when getting a resident from the hospital or rehab, we end up behind the eight ball, rushing to schedule home health services to address their wounds. This can also lead to readmitting residents to the hospital within 24 hours. In some cases, I will make sure that myself, a staff member, or family members sit with our residents while in the hospital to make sure someone can

6 Institute of Medicine, Engineering National Academies of Sciences, and Medicine, *Assessing Progress on the Institute of Medicine Report the Future of Nursing*, ed. Stuart H. Altman, Adrienne Stith Butler, and Lauren Shern (Washington, DC: The National Academies Press, 2016).

directly advocate for them."

The residential care manager has a vision when it comes to hospital treatment, especially in a rural area like Yavapai County where Prescott Valley is located.

"I just wish there was a special unit for the elderly, like there is the maternity ward," she says. "We – I mean the senior care profession – need to explore the possibilities, and the necessity, of a space where professionals are properly trained to evaluate these patients and, when called for, bring in caregivers to work with them. Having dedicated staff when elderly people enter the hospital would go a long way. If we keep the system as it is, we are just going to spend more and more time caring for human error."

Easterly points to research and case studies that address the benefits of smaller assisted living/care homes over larger facilities. A report carried by the National Library of Medicine in 2016 noted that larger assisted living accommodations typically suffer from low staffing levels that lead to poor quality of care – when higher federal and state staffing standards are met, the proportion of residents with pressure ulcers, physical restraints and urinary catheters decreased, and the quality of overall care increased.[7] Additionally, a litigation case study reported in the *Journal of Health Care Organization, Provision, and Financing* in 2018 found that patients' rights, clinical measures of poor quality and the subsequent success of outcomes were among the top grievances voiced by patients and caregivers at a large chain of for-profit nursing homes.[8]

Smaller home care facilities are often better equipped to support patients in daily living activities, to recognize and maintain their dignity and autonomy, and to provide them with a greater sense of control and choice in their routines, says Easterly. Yet, large assisted living options are very appealing, especially for the patients' children, who often make the decision to place their loved ones. Indeed, such facilities tend to be aesthetically pleasing, and offer a whole range

7 Institute of Medicine, Engineering National Academies of Sciences, and Medicine, *Assessing Progress on the Institute of Medicine Report the Future of Nursing*, ed. Stuart H. Altman, Adrienne Stith Butler, and Lauren Shern (Washington, DC: The National Academies Press, 2016).

8 C. Harrington and T. S. Edelman, "Failure to Meet Nurse Staffing Standards: A Litigation Case Study of a Large Us Nursing Home Chain," *Inquiry* 55 (2018).

of amenities, which can include fine dining, a fitness center and a salon. They can host hundreds of residents at a time, lodged across different floors and buildings, and sometimes have a registered nurse on staff. But very often, they are only able to provide patients with minimal levels of care. They will prepare meals and make sure to take it to the patients, do their laundry, do housekeeping, do stand-by showers and toilet, but when patients start requiring higher levels of care – for example they need to be changed, or they require to be moved with a Hoyer Lift – their needs could suffer due to staff shortages or a high resident to caregiver ratio.

Eventually, the patients' conditions can decline. Sometimes, as a result, they will have to be transferred and adjust to a new place. When that happens, some patients are unfortunately not able to tolerate such change and will decline rapidly. Moreover, large assisted living facilities tend to run on very short caregiving staff.

"The worst situation I have seen," Easterly says, "is one in which we were two caregivers and one MedTech for three floors, which is about 86 patients. On a good day, there might be five caregivers for that many patients." As a manager, Easterly understands the challenges of proper staffing. Hiring and retaining quality caregivers can be difficult; staff turnover is high across the industry.[9] "Even when people don't quit," she says, "there are many days that a person will not be able to come to work because they will have a family emergency, or another responsibility that will take precedent, and they won't show up at work."

Most caregivers are women who have care responsibilities in their private lives (e.g., children, parents, a spouse), while some may have another job or go to school. Adding to the staffing challenge is the low pay experienced by caregiving practitioners and staff. Economic concerns and financial incentives are among the areas given special attention in the National Library of Medicine report noted above – they are identified as being barriers to staffing reforms.[10] There will always be exceptions to the rule, and size – big or small – matters in assisted living home

9 Marley Brocker, "Golden Years: A Rebounding Economy, Aging Population and Healthcare Reform Will Likely Aid Growth," *Retirement Communities Industry in the US - Market Research Report* (Los Angeles, CA: IBISWorld, 2022).

10 Institute of Medicine, Engineering National Academies of Sciences, and Medicine, *Assessing Progress on the Institute of Medicine Report the Future of Nursing*, ed. Stuart H. Altman, Adrienne Stith Butler, and Lauren Shern (Washington, DC: The National Academies Press, 2016).

care. Easterly cautions that one size does not fit all, that a small home may be appropriate for one patient, while a larger home will work better for another.

"As a caregiver and manager, when I give a tour for a prospective resident, I am very honest with what we can and cannot do," she says. "It's important to the patient's well-being, and it's important to that patient's comfort-level that they are among people facing similar challenges. It's not beneficial to bring a patient into a setting where the majority of the residents are suffering from advanced dementia, while this person has full control of their faculties." In such case, Easterly advises, a large community might be a better fit. Honesty both ways is what is needed."

Easterly endorses integrated models that include tiered approaches to elderly care, believing them to be viable options for patients in need of health services. In such models, a patient may first join an independent living community, enjoying a level of freedom, including the opportunity to care for oneself while enjoying a range of amenities designed for their age group and physical and emotional standing. When the need for greater daily attention is required – assistance with showers, meals and medication management – an assisted living setting is more suitable. Physical or emotional incapacitation – such as dementia-related diseases – requires a higher level of care, an environment where special needs can be addressed and proscribed as appropriate. Such integrated models allow the patients to age in the same place, one that meets their individual needs for routine and stability.

Like each patient who may require a different level of care or means of treatment, the setting for such care can vary. What Easterly believes each level of home care shares in common is a reliance on honesty from their patients, and the ability to serve a specific health demographic. Meanwhile, the patient – and their loved ones – must rely on each care facility to meet, if not surpass, the highest standards of care, including the care team's ability to recognize special needs and provide the appropriate treatments in a dignified and trusted manner.

About the Authors

Estève Giraud

Estève Giraud is an assistant research professor at Arizona State University. Her research focuses on the integration of care theory and practices in food systems to enhance resilience and sustainability. Dr. Giraud has recently received two grants from ASU to explore the effects of gardening and cooking activities on dementia patients, and as a preventive solution for caregiver burn-out. At the university's Swette Center for Sustainable Food Systems, her research work focuses on organic agriculture and urban agriculture.

Dr. Giraud is also the director of strategic operations at Desert Haven Home Care, and a strategic advisor to The Zambakari Advisory. A native of France, she holds a Ph.D. in sustainability from ASU, and a master's in economics and management from University Pompeu Fabra (Barcelona, Spain), and a master's in business from Toulouse Business School (Toulouse, France).

Tammie Easterly

Tammie Easterly is the residential facility manager of Prescott Valley Assisted Living. She joined the Prescott Valley team in 2022 after serving for 15 years as operations manager at Sunrise Care Homes in Scottsdale, Arizona. A certified caregiver with a passion for senior healthcare and the well-being of her patients, she leads by example as an energetic and motivated team player.

At Villa Fiore, Easterly is responsible for the successful day-to-day operations of the facility. She oversees staffing, marketing, budgeting, maintenance and the home's innovative integrated resident behavioral and physical health services. Licensed as an assisted living manager in Arizona, she ensures Villa Fiore's full compliance with federal, state and local industry regulations and standards, as well as positioning the facility to offer the fullest range of evidence-based, effective care and services available.