

From Crisis to Care Partners: The Story of Mom

by Anonymous

My parents had been living independently at their home for decades, albeit recently with a few non-normal aging issues. Then, nine months ago, Mom suddenly landed in the hospital for a week, with vague and unspecified complaints. After a variety of medical approaches and frightening days in the ICU, it was determined mom was near the end. The hospital released her, mostly nonresponsive and on morphine, to go home on hospice status.

I lived three states away, but had flown back at the dire news. As the oldest of three siblings, I took charge and jumped into action. After meetings and signing papers, hospice services were put in place. Hospice would set up the hospital bed and bedside commode at home. They would provide visits from a nurse one to two times a week, someone to give her a sponge bath and wash her hair three times a week, and have her medicines delivered to us.

We didn't know how much time we had left with mom. "A week," is what one doctor said. All I had to do was find caregivers 24/7 to give care to her when we could not. This was a crisis and an emergency for the whole family. Dad wanted her at home. She had also begged to be at home.

So I called the home care office that my parents had signed up for a few years prior "in case" something happened "some day." The office barely had any staff available to offer us for shifts. I turned to the hospital list and began dialing, calling three more recommended home health agencies until I got one agency owner willing to meet the next day, on a Saturday morning, for an assessment. By Sunday late afternoon, the hospital bed and oxygen arrived, a nice, middle-aged caregiver was there from the agency, and mom would be appearing in the ambulance any minute. We were ready.

The caregivers started arriving at my parents' home around the clock, for 3-, 4-, 8-, sometimes 10- or 12-hour shifts. Mom's weakness and confusion required two of us at all times to turn her, prop her up, and get her disposable briefs cleaned up. Then there were mounds of laundry, clothes were cut up the back so we could get them on, small meals prepared, pills crushed into applesauce, and repeat. In reality, a third person was necessary to run errands, return phone calls and emails, keep meals available, and log visitors who assumed this was the end. I quickly became the "project manager" and stayed for three weeks.

After six weeks, to everyone's amazement and joy, Mom began to improve. She had physical therapy and began using a walker with a caregiver by her side at all times to assist her. Mom got strong enough to finally step up the two steps into the main living room. But, with her improvements, came a host of safety issues because her mobility and strength were limited. Mom barely slept at night and it was difficult for caregivers when

she was restless and wanted to get up while she was sleepy. The agency requested a lift chair, safety bars, a lift on the steps and another hospital bed (the first one had been returned). When these steps were not implemented in a timely manner, the agency canceled its services, much to our dismay. Two other agencies I had been in contact with provided a few caregivers, but not nearly enough to staff home care seven days a week.

Struggling to find caregivers, it felt like crisis after crisis. Difficult behaviors emerged from Mom – lacking sleep, frustrated, confused, she would lash out by throwing things or insulting people. Though they needed the assistance, my parents were bewildered, sometimes angry or distrustful about the constant stream of caregivers, friends and family coming through the house. Someone needed to manage it all, so I flew in several more times to set up care and address a variety of problems. Family and neighbors all pitched in to help out with various things.

We didn't really have a specific diagnosis for mom, but suspected some kind of dementia, possibly Lewy Body Dementia (LBD) or frontal lobe dementia. The learning curve for all of us was huge – about personal care, about dementia, about red tape, and about the shortage of home care workers.

Staying at their home in old age was my parents' preference. Though many people now asked why they were not going to move to a nursing home, we also heard people advise us that mom was improving because she WAS at home. We worried that a move to a nursing home could mean a fast decline for her.

The first agency had given me the name of a local woman, Beth, a PAC mentor to see if she could help. I put off calling her until I was desperate. I had only recently stumbled on Teepa Snow and her videos about working with dementia. After talking to her, Beth seemed like a good fit to assist our family in finding home care staff. I also called an agency that touted their use of the Teepa Snow GEMS philosophy. The agency said all of their caregivers were well trained in the various GEMS and Teepa Snow methods. I felt hopeful that we had finally found an agency that would understand mom.

But, there turned out to be more staffing woes. The new agency sent a young woman, who was completely new to home care. She talked a lot – too much – sharing with mom all the details of her financial woes, her life story, her boyfriend troubles, her kid's names, and where she lived. Dad didn't trust her. She had few boundaries, wandering into dad's office, looking at mom's medications (off limits to staff), and even spoke to mom's doctor at one point, asking for another medication to be prescribed for mom's restless legs. Two other women were sent by this agency, but within three weeks, it was clear that they weren't well-versed in Teepa Snow methods nor could they provide enough staffing for mom's home care. They gave us two weeks' notice for their services, which set off a crisis yet again. Unfortunately, it turns out, many agencies claim to be "trained" in Teepa Snow/Positive Approach to Care's methods when in actuality, the staff are merely required to watch a DVD or two.

"Not again!," I thought. But this time, I was more prepared. My mother was doing better, we understood her dementia cycles more, and we could sometimes predict which days she would be ultra-sleepy and confused versus days when she had mental clarity, enjoyed activities, and seemed genuinely happy. Beth assisted us all in understanding

dementia, and began training our family and caregivers in the Positive Approach to Care methods. Beth was a lifesaver, filling in herself for many shifts while we looked to put a team of care partners together. We all began working with mom differently, and it really seemed to be making a difference in how mom was doing. This is when I realized the difference of someone being trained in Teepa Snow/Positive Approach to Care methods and someone who has merely been exposed and made aware.

By this point, we had staffing from a range of sources: several agencies, private caregivers, and some occasional helpers, but we didn't have enough people to keep up with Mom's 24/7 care. She sometimes didn't sleep for 48 hours, then she was wobbly, confused, hitting, biting, kicking, and throwing things. Mom punched three women in the face when she was confused and frustrated, to my dad's horror and to her later denial due to her changing brain. Needless to say, everybody was getting frustrated.

Participating in one of Teepa Snow's "Ask Teepa Anything" webinars on Facebook live gave us information about starting CBD oil. We tried it in the evenings, and it seemed to significantly lower mom's anxiety and restlessness. Mom relaxed with the CBD drops and was less agitated, even became more interested in activities of daily life during the day. There seemed to be no negative effects, unlike some of her other prescription medications.

In addition, we gained some knowledge from a local geriatric neuroscience institute urging us to begin a new medication routine, which we did, with positive results for Mom.

For home care, we contacted yet another agency and hired some private individuals who worked well with Mom both on her needy days and her independent days. By now, we were very clear that any caregiver could not work for us until they had direct, hands-on training from Beth about understanding dementia. We heard from staff that it made a big difference to learn about what happens when the brain changes. They learned how to approach Mom and how to understand where her difficult behaviors might be coming from (brain changes). Mom felt supported instead of frustrated. She seemed happier and more engaged in daily life, as long as she had a trained, compassionate person nearby. Our work towards developing care PARTNERS was beginning!

One of those hires was a young woman who loved people living with dementia. She was energetic, creative, and trained in the Teepa Snow PAC methods by Beth. Another hire was a woman at a fulltime job who was also looking for some part-time caregiving work on weekends and evenings. She was so eager to learn about Teepa Snow PAC techniques that she took notes the first night on the job. Later, she said that mom seemed like a difficult client until she learned the PAC methods and had training from Beth. I hired another young woman who was energetic, creative and understanding. She was in college and said she watched Teepa Snow videos in her free time while she cleaned her room. In addition, I hired an older woman who liked to sing and do art as an "activities coordinator" for her elderly clients. We were building a team of Care Partners! It felt good.

We are in a much better position now with helping Mom in so many ways. We have had some glitches in the past few months with staffing, medications, and misunderstood directions, but for the first time in nine months, I can sleep all night at home and even when I visit my parents. I am not getting the emergency texts at night that mom fell or

something went wrong, or someone can't make it to the house. The last time I visited my parents a few weeks ago, mom was clearer and happier than I had seen her previously. Her mobility is much better, and on clear days, she is quite independent with her walker and personal care, usually putting things away all over the house or directing care partners to. When I think back about this long journey, it is amazing that Mom has gone from being unresponsive in a gurney on hospice status, to asking her care partners to keep her kitchen shelves and closets well organized. We think it is wonderful.

I work hard to manage the home care team I have put together, but it's worth it. There are nine regular staff (each one working 8-40 hours/week) and one Teepa Snow coach, Beth Tesfay, who trains every person BEFORE they even begin their first shift. Each Care Partner is PAC trained and understands that Mom doesn't sleep much at night, so they must expect to possibly be engaging in games or activities with her even if they are working a night shift. And, if she wants to get a sponge bath and get dressed between 2-4 a.m., that is OK. She does it herself unless she needs help.

Each Care Partner has a gift. One sings music and plays piano and does artwork. She has mom singing old hymns and fun songs, sometimes for an hour, with mom harmonizing even if it is a sleepy, confused day. One woman likes to cook and mom taught her to make deviled eggs because this woman discovered mom likes to peel the eggs. Mom is out on her front porch every day often listening to and watching birds, a favorite pastime. One woman is making kits with menstrual pads for girls in Tanzania so they can stay in school, and is working on having Mom help her when she can. Dad takes Mom on a golf cart down to their pond several times a week and that always brightens her day. Recently, the monarch butterflies have been active in the field nearby, so she goes out to watch them regularly, with a Care Partner assisting as needed. The Care Partners are also connecting to Dad, who also needs help and respite, because this has been very difficult for him -- her constant "Care Partner" -- seeing his wife of 62 years change so much.

But with the staff team in place, even Dad almost always sleeps through the night.

LIVING with dementia! Thanks PAC!!!!