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A Look Inside Dementia Care Facilities, by a Family Caregiver

Wednesday, October 10th, 2012 by Natalie

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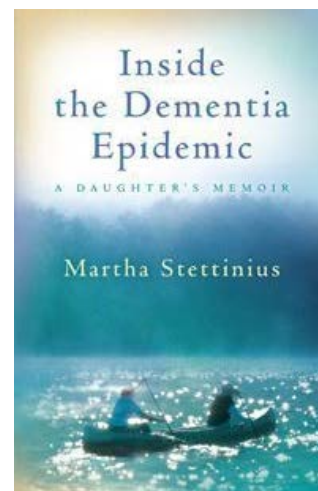
This is a guest post submitted by Martha Stettinius, author of the new book "Inside the Dementia Epidemic: A Daughter's Memoir."

At age 80, my mother is living with advanced dementia (vascular dementia and probable Alzheimer's disease), and I've served as her primary caregiver for 7 years. She's lived in my home with my husband and two young children, then in assisted living, a rehab center, a "memory care" facility, and now the dementia ward of a nursing home.

In the spring of 2005, my mother lived with us briefly, but she was unhappy and needed more independence, so we convinced her to move to a nearby assisted living facility. With mild cognitive impairment, she seemed afraid to go to activities, which were held in large groups that included the higher-functioning residents of the adjacent "independent living" facility. Many of the assisted living residents had some degree of dementia, but activities and care seemed tailored to the more independent residents. Staff did not receive extensive dementia training, and interactions were minimal. To my dismay, Mom spent most of her days watching TV.

Late in 2007, after falling and fracturing her pelvis, my mother suddenly became incontinent. The fall may have accompanied a small stroke. After Mom spent some time in a rehab center, the assisted living facility staff were not allowed (by their contract, and by our state's regulations) to physically help my mother change her adult diapers. I had to hire private aides to come in for several hours a day. The facility's case manager told me that my mother's needs had fallen into a "gray area." Shortly after that, when one of the private aides found Mom in bed one morning soaking wet and uncovered, her adult diaper ripped off, I knew it was time to move her. But where?

Mom would live in this memory care facility for nearly 3 years—years that seemed her happiest in a long time. Mom rewarded the staff's affection with lots of smiles and laughter. Firmly in the middle stages of dementia, she joined the activities, sparked a romance with one of the men, and generally enjoyed living in the moment, no longer tortured by awareness of her disease. Although she had her moments of agitation, the staff all received special training in dementia care, and they knew how to keep her calm and feeling safe. I toured a local "memory care" cottage, most impressed not with the plush, home-like environment—the light-filled windows, the green plants, the white, long-haired cat lounging on the hearth—or the seeming contentedness of the residents who listened to oldies on a CD—but the forthrightness of the administrator who gave me the tour. When I asked her, "At what point, exactly, would my mother have to move out?" she told me, "Residents must be able to feed themselves, and be able to walk for at least a few steps, for example from the bed to a wheelchair." That's the kind of answer I'm looking for, I thought. No "gray areas."



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By May of 2010, however, she seemed to have forgotten how to feed herself, and was losing weight. (She was also running out of savings, and the private memory care facility could not accept Medicaid.) I looked for a nursing home in the area that was on The Eden Alternative registry—a nursing home that follows the philosophy of person-centered care championed by Dr. Bill Thomas and his wife, Jude—or a nursing home that was part of the new Green House Project (also a Bill Thomas initiative), but the closest were 3 hours away. Mom moved into a local nursing home, where for the past 2 years she has received excellent physical care, if not the emotional sustenance and vibrancy one might find in an Eden Alternative nursing home or a smaller, more intimate home such as a Green House. She lives on the dementia floor, where staff members receive some specialized training, but residents in the final stage of dementia rarely enjoy individual attention or appropriate stimulation. Though she can no longer speak, and is immobile in a wheelchair, Mom still enjoys people and shares her brilliant smile. She is still “here,” and deserves to have a life that includes more than being spoon-fed her pureed meals, and napping through group activities.

I’m hopeful that our new National Plan to Address Alzheimer’s Disease will increase public understanding of Alzheimer’s and the need for specialized care, and that funding and answers will surface as more and more Americans fall prey to dementia. However, we need to press the Department of Health and Human Services to recommend a minimum number of hours of dementia training for health care providers and facility staff. According to the National Council of Certified Dementia Practitioners, individual states may or may not require dementia education, and their regulations vary by industry (home care, adult day care, assisted living, nursing homes, hospitals, and hospice). Some states, for example, require absolutely no dementia education for staff in the dementia units of assisted living. This must change.

About Martha Stettinius, the author:

Martha Stettinius is the author of the new book “Inside the Dementia Epidemic: A Daughter’s Memoir,” available at major online book retailers. She serves as a volunteer representative for New York State for the National Family Caregivers Association. For more information about the book, please visit www.insidedementia.com.

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This entry was posted on Wednesday, October 10th, 2012 at 8:02 am and is filed under [Aging](#), [caregivers](#), [Memory Care](#), [Senior Living News](#). You can follow any responses to this entry through the [RSS 2.0](#) feed. You can [leave a response](#), or [trackback](#) from your own site.

6 Responses to “A Look Inside Dementia Care Facilities, by a Family Caregiver”

1.  *Martha Stettinius* says:
October 10, 2012 at 8:41 am

Thank you, Senior Homes, for posting my guest blog. I will check back throughout the day in case anyone has any questions or comments.

2.  *Linda Austin* says:
October 10, 2012 at 9:40 am

I am very thankful my mother is in a nursing home where the staff receives dementia-care training. I love her “earth angels” who are so loving and

patient with all the residents and know how to handle difficulties in behavior that would floor me. I could not imagine placing her somewhere where the staff was not trained in dementia care, and this should be a requirement considering how common dementia is now and how confusing it can be for untrained caregivers. Thank God for the classes I took with the Alzheimer's Association.



3. *Mike says:*

October 15, 2012 at 11:49 am

Hi Martha,

Nice heartfelt article. Dealing with family members with dementia is very difficult. Thank you for your article. Dementia training should be mandatory for all states.



4. *Grabbing/pick-up tool says:*

October 17, 2012 at 12:26 pm

I would also like to Thank-You for writing such a heartfelt/informative letter. I had recently done private duty care for 3 years for a lady who had Parkinson's Disease and Dementia. As time went by her Parkinson's worsened as well as her mental status. Seems they went hand in hand. Her daughters too had done a lot of searching to find the "right fit" for their mom. They thought they did at a facility through Catholic charities. But as you stated one important factor is to make sure they are trained in dementia/alzheimer patients and not just a care facility. This first place also had a policy with medications that they had a 1 hour window before and after the appointed time to give it which I think is wrong especially with a Parkinson's patient who takes medication at certain times 5 or 6 times per day. Doing that according to their "window" policy really screws up the patient if one dose is given one hour late and the next dose is given an hour early this does no good for that later dose in controlling the jerking/tremors that a patient goes through. Well they ended up messing up her medications so bad/omitting a psychiatric one as well she ended up in the psych unit at the hospital for 10 days. She went back and in less than a week or so her daughters had her moved to a facility that specialized in the care of seniors with dementia/alzheimers. It's a nice place with nostalgic things because that's what they remember but the staff is trained especially to meet their needs. It's closer to both of her daughters homes and she seems to be happy. I agree more public awareness needs to be done to educate everyone of this awful disease. With great articles such as this published maybe were on our way.



5. *Marilyn Swenson says:*

November 25, 2012 at 2:45 pm

Visiting Angels is indeed a blessing. I needed someone to care for my mom who lives in Palm Beach Gardens, FL. She suffers from Alzheimer's and I live in England. I was able to choose the right caregiver for my Mom. The person was experienced and had excellent credentials. I have peace of mind knowing that Mom is in capable hands. You should check them out at <http://www.visitingangels.com/palmbeaches> (561-328-7611) if you need senior care services.



6. *Rehab Centers in Utah says:*

May 28, 2013 at 9:21 am

Thank you for your article! I appreciated it so much!

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