

Down the Road and Through The Woods

A Family Care Partner's Journey

by Linda Arndt



As the adult child living closest to my parents, I faced my father, who was determined to keep my mother in their home as long as possible; my mother, who now required more dementia related care than my father could provide; and, my siblings, who offered to help as much as they could given that they all had jobs, family and homes far from my parent's home.

Home was an isolated house in the north woods of Wisconsin that my father and mother had built and contentedly lived in for the last twenty-five years. The family agreed that in-home care was the least traumatic care option for our mother. With that agreement, my task of pulling together all the needed puzzle pieces required for in-home care began. And, with in-home care my mother remained living in that house, a house she no longer considered her home. Her home was just down the road, past the woods that stood in her path.

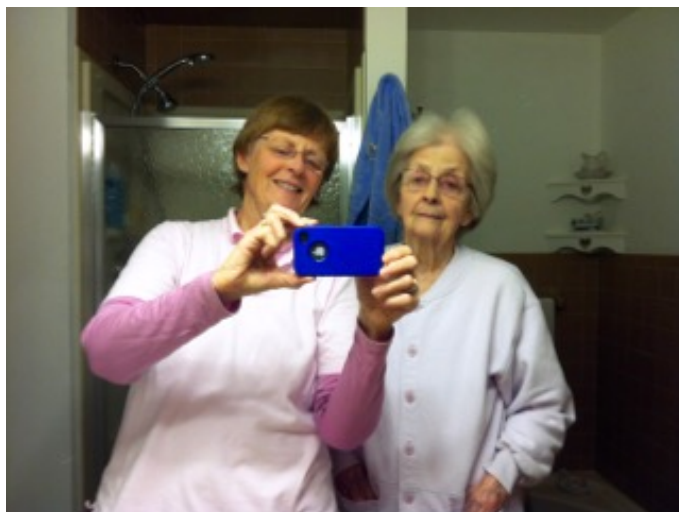
Little did I know that my task would involve many puzzle pieces hidden in a care system not only foreign to me, but also to my mother's doctors. I started listening carefully to anyone for any hint of where to find in-home help, or programs that may apply to my mother. I heard about private and agency caregivers who had experience with dementia patients, but little formal education or certification. I was directed to the Alzheimer's Association, local and national, and the county's Aging and Disability Resource Center (ADRC). Someone mentioned a dementia counselor who could provide guidance to us as long as my mother was not on a state funded program. I overheard a discussion that described a Medicare funded Personal Care program that required a doctor's order. It was all so confusing.

While my father depleted their savings paying for agency in-home care, I learned of an elder law attorney who could explain the rules and the financial formula that needed to be followed, so my mother could become eligible for Medicaid. Once on Medicaid, the Wisconsin IRIS (Include, Respect, I Self-direct) program could provide the funding that my father would need to continue in-home care. Any bit of information I obtained was pursued. Every phone conversation led to another

call. I was persistent and politely insistent as I became more informed about the options and costs for my mother's continuing in-home care.

We followed the rules set forth and eventually my mother was eligible for the state funded program. With the program money provided we had to cover many hours of care. Agency care was too expensive, so I found and built a team of private in-home caregivers. We lost our dementia counselor, but educated ourselves by using Teepa Snow's DVDs and attending several of her seminars. My father learned how to support his wife who no longer recognized him as her husband. We held regular staff and family care meetings. We discussed and learned care techniques to address my mother's physical and emotional needs. In my mother's case, the consistent use of these care techniques resulted in the discontinuation of behavior controlling drugs and their negative side effects. A program coordinator and a nurse checked on us every few months as we did our best to keep my mother comfortable in her home until her late stage dementia related death.

I had never personally cared for someone to the degree I cared for my mother, never experienced death up close and so very personal. Yet, I had been in charge of my mother's care and her care team for the last two years of her eight-year long dementia journey, in charge of something I started out knowing absolutely nothing about. Through it all, I did not really know if I was utilizing every program available to my mother and the ever-changing dementia picture she was presenting. I often felt as alone as my mother did. Sometimes, as we both stood before the bathroom mirror, neither one of us recognized ourselves. We both searched the mirror for those younger confident beings we remembered.



There had to be an easier way to find and utilize in-home care programs. At my mother's funeral service, I learned that Kitty Rhoades, Secretary of Wisconsin's Department of Health Services, was very interested in and proactive about the future of dementia care. I wrote the Secretary outlining several aspects of in-home care that I had found difficult to deal with, as well as recommendations from the

perspective of a hands-on family caregiver. (See partial listing attached) The Secretary was kind enough to acknowledge my letter and she forwarded my information to the committees addressing improvements and innovation in Wisconsin's dementia patient care.

We can help other families by being proactive. If we have lived it, we can share what we have experienced. I believe that in-home dementia care is going to be in high demand in the future as a cost effective and viable option. With adequate funding support, available resources specific to dementia care and a health care system functioning to provide uncomplicated access to both, the in-home care approach to this disease can be a blessing to many dementia patients and their families. For my mother and father, my family and for myself, it was the best option and had the best of outcomes, as my mother finally completed her eight-year dementia journey moving peacefully down the road and past the woods.

Issues and my recommendations to Secretary Rhoades:

1. Many elderly people do not have the support system or information gathering and problem solving skills needed to access program assistance.

Recommendation: There needs to be a single source of comprehensive dementia care program information. All primary care physicians must be aware of, promote and refer to this source of information.

2. It was very difficult to find qualified in-home caregivers.

Recommendation: Develop a certified dementia caregiver registry that can be accessed on-line.

3. My mother was prescribed several drugs to control difficult behaviors. The drugs caused lethargy, negatively affected mobility and suppressed her personality.

Recommendation: Dementia caregivers receive Positive Approach Care skills training/certification to decrease the need for behavior drug therapy.

4. Overnight care may be needed early in the disease process for those patients whose day/night activity clocks have reversed. Late in the disease process, nighttime care is as significant as the patient's daytime care. Funding was not available for overnight care.

Recommendation: Program funding, at all stages of the dementia disease process, provides for necessary overnight care without depleting the funding allotted for daytime care.

5. Once in a state supported program, and as more severe patient care issues became a reality, hands on patient care education was no longer funded.

Recommendation: In-home dementia care programing options provide continuous access to coaching/consultation resources.

